

Section I Introduction

“But, to me, the hope that she could survive was what kept me going. So I don’t feel like false hope was even an issue. I don’t think any hope is false.” - Focus group participant

In Utah, approximately 500 children under the age of 18 die each year. Of this number, about 180 die of life-threatening conditions such as cancer, congenital anomalies, heart defects, and other progressive conditions. Many more children suffer from serious and progressive conditions that may extend over many years and require extensive nursing care. The current system of care for children with these conditions does not address their needs. Families caring for a child with a serious life-threatening illness are often under extreme emotional, physical, and financial stress. Access to palliative care and support services is limited. In addition, the current system of pediatric care in Utah and in the rest of the U.S. unintentionally drives up the cost of medical care for this group.

Although about 94 percent of children in Utah have some type of health insurance coverage¹ (including Medicaid and CHIP), many policies cover inpatient hospital care but provide only limited coverage for often less expensive home care. Very few policies offer supportive services to the family. Physicians rarely recommend hospice care because the selection of hospice precludes the pursuit of curative treatment. Hospice also requires a declaration the child is likely to die within six months, which is difficult for the physician to predict and for the parent to accept. The lack of hope for cure inherent in the hospice-care model, adopted by Medicare, Medicaid and insurance companies, makes this an inappropriate model for children. This gap in coverage and a number of other factors lead to a fragmented system of care, which drives up cost while ignoring the needs of the child and family for respite, emotional, and financial support. These factors include the following:

- Current administrative practices that eliminate the possibility of combining potentially curative care with palliative care.
- Beliefs that cure is the only medical success.
- Physicians who are reluctant to admit that the child’s life expectancy is limited, therefore hindering the family’s access to supportive services through hospice.
- Health plan benefits that make skilled nursing and hospice care mutually exclusive.
- Health plans, including Medicaid, which will pay for high-cost institutional care but will provide only limited home-care benefits.

¹According to the 2000 Utah Child Health Survey published by the Utah Department of Health, children with special health care needs are more likely to be covered by some type of health insurance. Only 4.1% of these children are uninsured compared with 6.5 percent overall.

- Lack of up-to-date information and systematic channels to information regarding the child's disease, the level of care required, and resources and benefits to help families make informed decisions.
- Lack of knowledge of symptom management and inadequate support of the caregiver that leads to crisis management and family disruptions.
- Lack of pediatric expertise among home health, hospice, or pain medicine providers.
- Lack of education in medical schools about the care of dying children and the few opportunities to gain experience in the care for such children.
- A widespread cultural belief that it is unacceptable for children to die.
- Lack of training and resources for clergy and volunteer clergy who are expected to provide spiritual support to families who are experiencing the loss or serious illness of a child.

Through the PACC® grant and the generous support of Congress, the Centers for Medicare and Medicaid Services and Children's Hospice International, the Utah Department of Health in conjunction with citizens, parents of children with life-threatening conditions, and other public and private agencies have designed a plan to address these issues. This plan is outlined in Utah's application for a Section 1115 Research and Demonstration as delineated herein. We believe that this proposal will not only better serve children with serious and life-threatening conditions and their families, but will also make effective use of taxpayer dollars.

Section II

Promoting HOPE Advisory Council, Mission and Goals

“When you get down to the end, you just need to know that you have a team of people that are working with you and that you don’t have to go over it with them every time somebody walks into the room. I got more information about the kind of oil I need to put in my car than what they put in my son. Seriously—we need more information, more choices!” -Focus group participant

A. Advisory Council

The Utah Department of Health, Division of Health Care Financing, led the partnership that developed the design of the Promoting HOPE for Utah Children program for which this application is submitted. The Promoting HOPE Advisory Council has met at least monthly since December 2000 to develop the plan. In addition to the members of the Advisory Council many other persons volunteered their help in this effort.

The Promoting HOPE Advisory Council represents a wide range of community partner organizations and agencies, including the following:

- Angel Watch - full-service pediatric hospice division of Utah Heritage Hospice.
- Candlelighters for Childhood Cancer - non-profit organization that provides advocacy, education, emotional and practical support to families whose child has cancer.
- Community Nursing Services - community-based home health care agency and pediatric hospice services.
- Family Voices - parent advocacy, information and education services.
- Huntsman Cancer Institute - National Cancer Institute, designated cancer research center.
- Intermountain Health Care (IHC) Home Care - network of 10 full-service home care agencies, which includes dedicated pediatric home care agency.
- Partnership to Improve End-of-Life Care in Utah - coalition of institutions and persons committed to improving end-of-life care for all Utahns.
- Primary Children’s Medical Center (PCMC) - pediatric referral center for the Intermountain West, covering the largest geographic service area of any children’s hospital in the U.S.
- United Health Care - managed health care organization that contracts with Medicaid.
- University of Utah, School of Medicine, Department of Pediatrics - educates medical students, pediatric residents, postgraduate fellows, child health care professionals, nurses, etc.

- Utah Department of Health, Division of Community and Family Health Services, Bureau of Children with Special Health Care Needs - Title V agency responsible for promoting and protecting public health. Also provides services for children who have or are risk for chronic physical, developmental, behavioral, or emotional conditions.
- Utah Department of Health, Division of Health Care Financing - lead agency for the PACC grant and the single state agency responsible for administering the Utah Medicaid program.
- Early Intervention Research Institute, Utah State University - Engages in research and education on issues related to children with special needs and their families.
- Intermountain Pediatric Society - the Utah Chapter of the American Academy of Pediatrics.

The Advisory Council adopted a distinctive logo (see cover) and name for the project: “Promoting Hospice and Optimal Palliative Efforts for Utah Children,” also referred to as “Promoting HOPE.” The name and logo clearly identify the project’s purpose and message of hope for the parents and child in the provision of care that is palliative and which mirrors hospice principles of care.

B. Mission

The mission of the Promoting HOPE for Utah Children program is to make coordinated, holistic care and services accessible to Utah children with life-threatening illnesses and to preserve the quality of life for the child and family throughout the illness and beyond.

C. Definitions

The Advisory Council adopted the following definition: “a child with a life-threatening condition means a child between the ages of 0-18 who has a medical condition so serious it is unlikely the child will survive childhood as determined by the treating physician.” Examples include conditions

1. for which cure is possible, but not certain (e.g., cancer);
2. for which there is no known cure, but where treatment may prolong life and allow participation in normal childhood activities (e.g., cystic fibrosis);
3. which are progressive (no curative options) and where treatment is palliative from the beginning (e.g., genetic neurodegenerative disorders, muscular dystrophy); and
4. Which are not progressive, but which can cause life-limiting complications (e.g., severe cerebral palsy).

D. Goals and Objectives

The Advisory Council adopted the following goals and objectives for the Promoting HOPE program:

1. Expand the support services available to children diagnosed with a life-threatening illness and to their families by financing the expansion through a Medicaid demonstration model which will permit -
 - a) Reimbursement for palliative care and support services not currently covered by Medicaid; and
 - b) Access to the child currently eligible for Medicaid as well as the child in a family whose income and resources exceeds current Medicaid limits.
2. Maintain budget neutrality for federal dollars provided to the Utah Medicaid program by -
 - a) Covering supportive services and interventions to reduce the utilization of costly inpatient and outpatient hospital services;
 - b) Assisting families to better utilize current health insurance benefits;
 - c) Charging the family a fee for the supportive services;
 - d) Better utilizing supportive services currently available in the community; and
 - e) Obtaining donations to help defray the cost of supportive services that may not be eligible for Medicaid reimbursement.
3. Improve use of other formal and informal community supports by collaborating with the community in -
 - a) Developing a coordinated system of care, so any child diagnosed with a life-threatening illness is referred to the program, regardless of where the child is diagnosed;
 - b) Establishing a protocol so each family has access to information at the point of diagnosis to help them make informed decisions; and
 - c) Supporting the family choice and options in a coordinated manner among all parts of the system, including the primary care physician, the specialist, the hospital, home care provider, insurance carrier, school, *etcetera*.
4. Increase the satisfaction and stability of families who have a child diagnosed with a life-threatening illness by -

- a) Implementing the program in accordance with project principles (see below);
- b) Working with licensing agencies and other entities to establish standards for pediatric palliative care providers who participate in the program;
- c) Working in collaboration with community partners to develop training opportunities to for pediatric providers, volunteers, and community spiritual leaders to better serve the target population; and
- d) Measuring family satisfaction and seeking improvements based on an ongoing evaluation and quality assurance process.

E. Guiding Principles for Promoting HOPE for Utah Children

The Advisory Council formulated the following principles to guide the administration of this program:

1. All decisions in the delivery of care and services should be made in the child's best interest.
2. There must be respect for the dignity, privacy, desires, culture, and choices of the child and family.
3. Adequate and realistic information must be readily available and updated as circumstances change so families can make informed decisions.
4. Therapy, including alternative or non-traditional treatments, which may realistically be expected to improve the patient's quality of life, should be accessible. While public funds may not be used to pay for alternative or nontraditional treatments, other resources should be explored.
5. The preferences of the child and the family must be honored, and adequate counseling and support offered when the physician or the multi-disciplinary team recommends a change in the course of treatment.
6. Services must be developmentally appropriate, flexible, and sufficient in duration and scope to meet the needs of the child and family.
7. Services must be provided in the most appropriate setting, based on the need and choice of the child and family.
8. The child and family must be able to choose whether the child's medical care is overseen by the primary care provider or by specialists.
9. To further continuity of care, services must be planned, inter-disciplinary and coordinated among all care givers, whether provided in the hospital, nursing home, medical office, home, or other setting.

10. The needs of siblings and other family members should be considered and addressed.
11. Services must be provided in accordance with accepted professional practice standards.
12. Caregivers, including volunteers must also be offered adequate training, support, and the opportunity for bereavement by their organizations and the community.
13. Families must participate in the cost of care and services to the extent they are able.
14. Public and donated funds should be used to assist families with limited resources and, as feasible, to reduce the possibility of family disruption and impoverishment because of the high medical cost of the life-threatening illness.
15. Resources including public funds, donations, and volunteers must be used effectively and efficiently to meet the greatest need.
16. Services should be available statewide and to children in neighboring states who receive acute care in a tertiary facility in Utah, to the extent possible.
17. Duplication and overlap with other program areas should be minimized to streamline service delivery and improve access for all who qualify.
18. System improvement must be based on ongoing evidence-based study and evaluation.
19. There must be a safe and supportive social and legal climate for parents, physicians and the interdisciplinary team when decisions are made in the best interest of the child.

Section III

Overview of Utah and Current System of Care for Children

“The only way to get help is... to destroy yourself financially and sink to such a poverty level that you can never get out of it...” -Focus group participant

According to the 2002 Kids Count Data Book², “Utah is the third-best state in the country for children despite a rising number of low-birth weight babies, high school drop-outs and single-parent families.” The fact that children represent 34 percent of the Utah population is an important reason for Utah citizens to support programs that focus on the needs of children and their families. Although Utah’s record on initiating and supporting programs to improve the lives of children is better than many other states, there is still much room for improvement. Fortunately, Utah can build on its past success to achieve improvements in the care of children with life-threatening illness--the focus of the Promoting HOPE demonstration proposal.

This section describes some of the relevant demographic and economic aspects of the State of Utah to provide a better picture of the target population within the context of the state population and environment. It also includes a description of the programs and agencies that are involved or which may play a role in improving the climate for Utah children, including the target population.

The Utah Medicaid agency has collaborated with a number of other state agencies including the Title V agency, the Department of Human Services, and local community health centers, in a number of initiatives to improve services for Utah children. These include the Medical Home Project, the Early Childhood Project, CHIP, Home and Community-Based Waiver programs for children who are technology dependent and another for individuals with developmental disabilities. Utah’s experience with home and community-based waivers, 1915b waivers for managed care programs, and the recently approved Primary Care Network Section 1115 Research and Demonstration Program, are indicators of the Medicaid agency’s experience and capacity in implementing a variety of waiver programs. The Utah Medicaid agency has also worked closely with various health care agencies, support organizations, and interested parents (also described in this section) in developing the current proposal for children with life-threatening conditions.

Utah’s relatively small population, recent initiatives to improve services for vulnerable populations, and the Medicaid agency’s experience in working collaboratively with other groups and agencies all help demonstrate the strength and capacity to successfully carry out the proposed 1115 research and demonstration model for children with life-threatening conditions.

A. Demographics

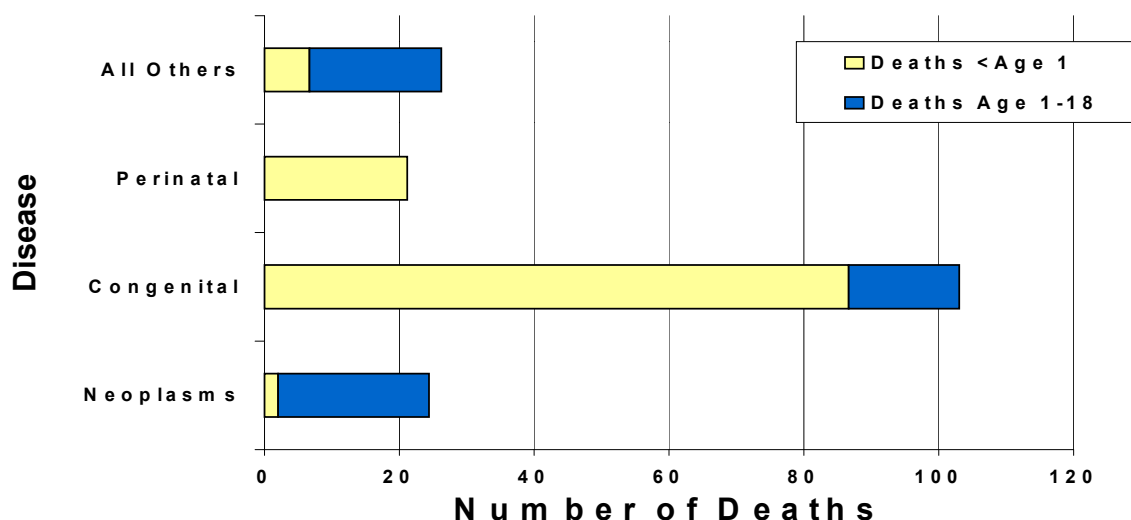
Utah is primarily an urban state with a population of 2.2 million. About 80 percent of the population lives in an urban area that stretches 100 miles in a corridor along the Wasatch Mountain Front (part of the Rocky Mountain range) from Ogden in the north to Provo in the south. Salt Lake City, the state capital and the major urban center, lies in the center of this urban

²2002 Kids Count Data Book, Annie E. Casey Foundation

corridor. Nationally, Utah has the youngest population and the highest number of children per household. According to the 2000 census, 34 percent of the population was under the age of 18 compared to the national average of 26.5. The average household size in Utah was 3.15 compared to 2.63 for the national average. The 2000 census indicates there are 719,080 children in Utah under the age of 18, which represents about one percent of the population of all children in the United States. Blacks, Hispanics, Asians, and American Indian children make up less than 10 percent of the child population in Utah. Hispanics are the largest minority group and constitute about 7 percent of the total child population.

1. **Utah Child Deaths** - The death rate among Utah children age 1-14 is 27 per 100,000³ which is slightly higher than the national average of 25; while the infant mortality rate is 5.8 per 1000 live births which is lower than the national average of 7.2. In 1999 about 500 children died in Utah of all causes. The majority of deaths or 220 were among children under the age of one. Based on the list of life-threatening conditions (Appendix A-1), an average of about 180 children in Utah under the age of 18 died annually, between 1990 and 1998, of one of these identified conditions, of which two thirds were children under the age of one.

Figure III – 1: Distribution of Utah Child Deaths from Life Threatening Conditions



2. **Medicaid Child Deaths** - Between 1997 and 2000, about 53 children enrolled in the Medicaid program died annually of one of the designated life-threatening conditions listed in Appendix A-1, which represents about 29 percent of all such deaths in Utah. Thus, even though the Utah Medicaid program covers only 18 percent of the child population, a disproportionate number of children on Medicaid suffer from a life-threatening condition that results in death. Similarly, 29 percent of hospital discharges for children in Utah with a life-threatening diagnosis in 1999 were for children covered by Medicaid.
3. **Children with Special Health Care Needs** - Based on a questionnaire adapted from the

³ 2000 Kids Count Data Book, The Annie E. Casey Foundation

Foundation for Accountability (FACCT) “Living with Illness” questionnaire, 12.6 percent or about 90,000 children in Utah have a chronic disability, illness, or condition that requires special health care beyond that of children generally. These conditions range from very serious life-threatening conditions that may result in early death to mild conditions such as attention deficit disorders. Of the 90,000 children with a special health care need, we estimate 9000 have progressive conditions that may or may not be life-threatening. It is difficult to ascertain the number of children in Utah who may not survive childhood because of a “life-threatening condition.” Nevertheless, based on extrapolation from Utah Medicaid claims data, we estimate that each year, 750 to 1000 children may be defined as individuals not likely to survive childhood, i.e., attain age 18, the definition of the Promoting HOPE target population. (See Section IV A) for a more detailed analysis.)

4. **Economic Conditions** - The average household income for Utah families in 2000 was about \$47,000, which is higher than the national average. In the Utah survey of children with special health care needs, median income for such families was similar. However, since Utah families are relatively large compared to the national average, Utah ranks considerably lower when states are compared on the basis of per capita income. In 1998, only 8.7 percent of children lived in households under 100 percent of the poverty level and only about 8.5 percent were without health insurance coverage. More recently, because of the CHIP program, only 6 percent of Utah children are not covered by a health insurance plan and only 4.1 percent of children with special health care needs are without health insurance coverage.

B. Medicaid

During 1999, based on the EPSDT 416 Report, about 130,000 unduplicated children were enrolled in the Medicaid program during the course of the year, representing about 18 percent of the child population in Utah. The Utah Medicaid program covers categorically needy and medically needy individuals. Children up to age six living in households with income at or below 133 percent of the federal poverty level and those up to the age of 18 living in households with income at or below 100 percent of the federal poverty level currently qualify for Medicaid. Utah has tied Medicaid and Temporary Assistance to Needy Families (TANF) so that mothers and children receiving services through TANF also receive Medicaid without a separate application process.

1. **Medicaid Hospice and Home Health Services** - The Utah Medicaid program covers hospice services in accordance with the Medicare/Medicaid policy and requirements. However, in 1999 only about 3 children in the Medicaid fee-for-service program received services from a hospice agency. Although hospice is a covered service in the Medicaid HMO contracts, very few children enrolled in an HMO were served by a hospice agency. Medicaid payments for hospice services are based on the methodology used in setting Medicare rates.
2. **1915b Waivers** - Approximately 70 percent of children enrolled in the Medicaid program are enrolled in an HMO through a freedom-of choice [1915b] waiver, which the Utah

Medicaid program has administered since 1983. On July 1, 1996, enrollment in an HMO became mandatory for all persons living in the urban areas along the Wasatch Front, regardless of age or eligibility category. Of the clients enrolled in managed care plans in FY2000, 82 percent lived in urban areas and 18 percent lived in rural areas. Between 1996 and 2002 the average monthly number of adults and children enrolled in Medicaid managed care plans varied from 72,000 in FY 1999 to 92,000 in August 2002. The number of managed care plans contracting with Medicaid has also varied from five in FY 1999 to three plans in September 2002 (see table below). In March 2002, IHC Access, AFC, and Healthy U coverage area extended to all four urban counties, while United was an HMO option in only three of the urban counties.

Table III - 1: Distribution of Medicaid Enrollees in Medicaid Managed Care Plans

	September 2002	
	Number	Percent
IHC Access	38,697	46%
United Health Care of Utah	0	0
American Family Care (AFC) Molina	34,831	35%
Healthy U	18,430	20%
Total	91,958	100%

In September 2002, the contract with United Health Care terminated and IHC Access became a preferred provider network, instead of a Medicaid contracting HMO. This means that Medicaid enrollees will have access to the IHC network of providers, while the Division of Health Care Financing will perform administrative functions related to the plan, such as payment of claims. The managed care plans offer all Medicaid State Plan services with the exception of long-term care, pharmacy, dental, mental health, chiropractic, and non-emergency transportation services.

Mental health services are provided under a “carve out” managed care program, known as the Utah Prepaid Mental Health Plan (a 1915b freedom-of-choice waiver program). The program has been in operation since July 1, 1991. Medicaid clients in all but one county must obtain mental health services from the contracting Prepaid Mental Health Plan that covers the client’s county of residence. The Bureau of Managed Health Care in the Division of Health Care Financing has primary responsibility for administering both 1915b waiver programs.

3. **1915c Waivers** - Utah has a number of approved Home and Community-Based Service (HCBS 1915c) waiver programs that serve children who may also be diagnosed with a life-threatening condition. These include a HCBS waiver program for technology dependent / medically fragile children, known as the Travis C. Waiver, implemented in 1995 and recently amended to serve 110 children under the age of 21. The Division of Health Care Financing (the single state Medicaid agency) and the Division of Family and Community Health (within the Utah Title V agency) jointly operate this waiver. Of the 110 children enrolled, approximately 30 may also have a life-threatening condition. The HCBS waiver program for individuals with developmental disabilities/mental retardation,

implemented in 1987, currently serves about 3600 persons, of whom about 1000 are children under the age of 18. We estimate about 5 percent of these children may also have a diagnosis that would be considered life threatening. The Division of Health Care Financing contracts with the Division of Services for People with Disabilities, in the Utah Department of Human Services to administer the HCBS waiver for developmentally disabled persons.

4. **Primary Care Network - Section 1115 Research and Demonstration Model** - Utah recently received approval to implement a new Section 1115 Research and Demonstration Model that will allow the State to address health care access for low-income working adults who do not have health care coverage. This program will allow the state to cover approximately 25,000 individuals, providing access to primary and preventive care as well as some emergency coverage. The benefit plan includes primary care physician office visits, flu immunization, pharmacy, urgent care visits, emergency room visits, lab, x-ray, ambulance transport, medical equipment, medical supplies, oxygen, basic dental care, hearing tests, vision screening, but not eyeglasses. There will be an annual enrollment fee plus co-payments similar to those required by enrollees in the CHIP program. This program was approved in record time. It was implemented in July 2002 and is administered by the Children's Insurance and Access Initiative Program.
5. **The Utah Medicaid Early Childhood Service** - In the year 2000, the Utah Medicaid program implemented an enhanced delivery system of child development services for children born to women enrolled in Medicaid. This statewide case management service is provided to children from birth to age four by registered nurses employed by or under contract with local health departments. Using a screening tool developed specifically for the target group, the nurse assesses the child for risk factors that may impede healthy development. If risk factors are identified, the child is referred to community or state resources that best meet the needs of the child. In the absence of another case manager, the nurse continues to provide follow-up case management, as necessary and appropriate.

C. Utah CHIP Program

The Utah CHIP program was implemented in 1998 and has served almost 50,000 children to date. Children under the age of 18 are eligible for the program if the family income is below 200% of the federal poverty level and the child does not have other health insurance. A child, whose family is offered an employer-sponsored health plan, may be eligible if the cost of coverage exceeds five percent of the family's gross income. Because of a shortfall in state revenues, enrollment in the CHIP program was frozen on December 14, 2001. At the time 26,500 children were enrolled. An open enrollment period began in the summer of 2002. The average length of stay on the CHIP program is 11 months. Approximately 33 percent subsequently enroll with employer-sponsored health insurance. About 20 percent of the cases are reopened for CHIP, another 18 percent become eligible for Medicaid, and about 5 percent leave the program because of a move, the death of a child, the child reaching age 19, or family income exceeding the income threshold. The disposition of the remaining cases is unknown.

D. Services for Children With Special Health Care Needs

The Utah Department of Health, Division of Community and Family Health Services is the Title V agency for Utah. They administer a number of programs with the goal of reducing illness, disability, and death from adverse pregnancy outcomes, chronic diseases, disabling conditions, injury and violence, nutritional disorders and vaccine-preventable infections. The Bureau of Children with Special Health Care Needs, within the Division of Community and Family Health Services, provides services for children who have been or are at risk for a chronic physical, developmental, behavioral, or emotional conditions. This includes children who also require health and related services of a type or amount beyond that required by children generally. The Bureau of Children with Special Health Care Needs provides direct care through specialty clinics through the state- population-based newborn and hearing screening, case management, and systems development.

The Bureau has successfully collaborated with the Division of Health Care Financing on numerous projects over the past few years to develop resources and programs for special needs children. A memorandum of agreement is currently in place and formally acknowledges the mutual interest and long-standing commitment of both agencies. Since 1995, the Division has contracted with the Bureau to assist in the administration of the HCBS Waiver for Medically Fragile-Technology-Dependent Children. Care coordinators through the Bureau of Children with Special Health Care Needs manage the day-to-day operation of the waiver program and work closely with families and provider agencies.

1. **Utah's Collaborative Medical Home Project**, funded through a three-year Maternal and Child Health, Medical Home Development Grant, began operation in April of 2001 to develop and implement a statewide system to support medical homes for children with special health care needs in primary care settings. One component of this project is the development of a website as a readily available tool for best practice guidelines, resources, care coordination, patient information, funding mechanisms and other related medical home information. Additionally, in 2001, Utah was one of 11 states selected to become a Medical Home mentor state through the American Academy of Pediatrics National Medical Home Conference. Members of the Utah team represent the ongoing collaboration within the state with representative from Medicaid, the Utah Chapter of the American Academy of Pediatrics, Family Voices, primary care pediatrics, and the Bureau of Children with Special Health Care Needs.
2. **Birth Defects Registry** - In July 2001, the Pregnancy Risk Line / Birth Defects Registry Program was relocated to the Bureau of Children with Special Health Care Needs and renamed the Teratology and Birth Defects Program. The new physical location and organizational placement greatly facilitate the program's relationships with other Bureau programs as well as with key pediatric providers at the University of Utah Medical Center in specialties such as Genetics, Pediatrics, and Maternal and Fetal Medicine. These changes have allowed improved education and outreach from the program to families and staff, as well as improving consolidation, coordination and tracking of genetic data.

E. Utah Health Care System for Children

1. **Children's Hospital** - Primary Children's Medical Center is the quaternary medical center serving children in the intermountain region and located in Salt Lake City. Founded in 1922, it is currently owned and operated by Intermountain Health Care (IHC), a not-for-profit health care system, also based in Salt Lake City. Primary Children's Medical Center is the pediatric referral center for the entire Intermountain West covering the largest geographical service area of any children's hospital in the United States and equipped to care for children and adolescents with complex illnesses and injuries. The 232-bed facility features world-renowned medical staff, as well as state-of-the-art equipment and facilities. The medical center is affiliated with the Department of Pediatrics of the University of Utah School of Medicine. As such it is one of only a few examples of a freestanding children's hospital located on the campus of a medical school and physically attached to a university hospital. In 1998, Primary Children's Medical Center provided nearly \$6.4 million in uncompensated charity care. Primary Children's Medical Center has the highest acuity pediatric patients of any hospital in the state and the sixth highest acuity nationally of any children's hospital. In 1999, 1,547 or 71% of the 2,182 hospital discharges for children under 18 with a life-threatening condition were from Primary Children's Medical Center.

Physician sub specialists are available for tertiary surgical and medical care for any medical condition that occurs in children. Physicians within the Department of Pediatrics of the University of Utah Medical Center manage patients with life-threatening and/or terminal conditions. In addition, physicians partner and collaborate with local community providers throughout the state in managing these complex medical conditions so that the children can remain at home or in their local community for much of their ongoing care. Primary Children's Medical Center has over 350 outreach clinics throughout the region each year. Specialists in the area of palliative pain control for children are available at Primary Children's Medical Center and can manage patients in rural areas by communications with local home care agencies and community physicians.

- a) **Family-Centered Care** - Primary Children's Medical Center has adopted a family-centered care philosophy: *to care for the whole child within the context of the family by an informed community of care givers*. The family centered care principles involve a system-wide approach to pediatric care based on the assumption that the family is a child's primary source of strength and comfort and that parents and other close family members are experts on their own children and hold essential information that can enhance children's health care. They acknowledge that involving families in hospital planning, evaluation, and policy-making improves children's care and that best practices are shaped by families and professionals working together. To further these principles the hospital funds positions of parent support coordinators, has established a Parent Advisory Committee and family resource centers.
- b) **Pain Services Department** - Primary Children's Medical Center has committed dedicated personnel and other resources to a comprehensive Pain Service Department. The new department collaborates with physicians in other departments in a focus on all aspects of acute, chronic, and palliative pain management, including symptom management, education, and alternative pain therapies in collaboration. This means

that children who receive care in any part of the hospital, from inpatient to outpatient services, will have their need for pain and symptom managed with the same standard of care and the same providers. Patients and families have 24-hour access to pain and symptom management services 365 days a year.

- c) **NACHRI** - Primary Children's Medical Center is a member of the National Association of Children's Hospitals and Related Institutions (NACHRI), a not-for-profit member organization. The Association is participating in a three-year national initiative to improve the care of children living with life-threatening conditions. The project, directed by Education Development Center, Inc., of Newton, Massachusetts, brings together seven NACHRI member hospitals as pilot sites. Each hospital has committed to develop quality improvement efforts aimed at meeting challenges in providing care to this population of children and their families. New curriculum materials for health care professions on topics such as pain and symptom management, family involvement in decision-making, ethics and law, communications skills and bereavement will be developed and tested in the pilot sites. NACHRI will serve as a liaison and communication link between the project and the broader NACHRI membership, advise on design and implementation of project segments, highlight best practices from NACHRI member hospitals and share project outcomes with NACHRI members. A network of palliative care contacts in member hospitals has been developed to support these activities.
2. **University of Utah, School of Medicine**, Department of Pediatrics is affiliated with Primary Children's Medical Center and is responsible for the pre-doctoral, graduate, and continuing education of physicians; the graduate and postdoctoral education of biomedical scientists; and the training of other health professionals. The school emphasizes high quality programs that address national priorities, such as the need for generalist and academic physicians, rural practitioners, basic biomedical scientists, and selected subspecialists. The Department of Pediatrics is an international leader in the care of children. The Department is committed to education for medical students, residents in pediatrics, postgraduate fellows, and child health professionals, nurses, and nutritionists. Department faculty has grants and contracts in excess of \$3 million per year at present. Research teams within the Department of Pediatrics are actively involved in investigation leading to the prevention of childhood disease.
3. **Huntsman Cancer Institute** is a world-class cancer research center founded in 1995 by a donation from the Jon M. Huntsman family. Located on the University of Utah campus in Salt Lake City, its mission is to understand cancer from its beginnings to use that knowledge in the creation and improvement of cancer treatment to relieve the suffering of patients and to educate the public about cancer risk, prevention, and care. The Institute is a National Cancer Institute-designated cancer center, which means that it meets the highest national standards for cancer research. Huntsman Cancer Institute is a member of the National Comprehensive Cancer Network, a coalition of leading cancer centers that set standards for cancer care.

F. Home Health and Hospice Agencies

There are at least five home care agencies in Utah that specialize in pediatric care. Two of these usually serve children with life-threatening illness under a home health, rather than a hospice license, because of a widespread reluctance to select hospice as an option for children. Between 1999 and 2000, these two agencies (Community Nursing and IHC Home Care) had a combined caseload of about 300 children who had a potentially “life-threatening” diagnosis as defined in Appendix A-1. There are about 50 licensed home health agencies in Utah and about 17 licensed hospice agencies, of which 9 are also licensed as home health agencies. In a recent survey of the licensed hospice agencies, about 8 indicated they had served a total of 21 children during the past year, but it was not clear whether the children had been served under their home health or hospice license.

1. **Community Nursing Service** - Established in 1929, Community Nursing Services (CNS) is Utah’s oldest, freestanding, non-profit, community-based home health care agency. It provides home health care and related services to clients in the Greater Salt Lake Area and throughout Utah. CNS is part of the Utah Home Health Coalition that includes ten health care agencies throughout Utah. The mission of Community Nursing is to assist individuals to attain health care goals, while maintaining independence and dignity, through appropriate home health care and supportive services. Its pediatric hospice and palliative care program, Kaleidoscope Kids© has been providing care to Utah children with a life-threatening illness since 1994. Kaleidoscope Kids© incorporates both a concept for caring and a system of comprehensive interdisciplinary, family-centered services.
2. **IHC Home Care** is a network of 13 full-service home-care agencies in Idaho and Utah operated by Intermountain Health Care (IHC), a not-for-profit health care system that accepts all patients regardless of their ability to pay. It is based in Salt Lake City and offers patients a wide array of home health services including an on-call service to patients 24 hours a day, 365 days a year. IHC Home Care includes a pediatric program that is JCAHO certified to provide services for children 0-18 years of age. As the only dedicated pediatric home care agency in the State of Utah, it offers skilled and private duty nursing, case management, certified home health aides, physical therapy, speech therapy, occupational therapy, respiratory services, infusion pharmacy, medical social work, expression therapy, registered dietitians, and home medical equipment and delivery.
3. **Angel Watch** is the full-service pediatric hospice division of Utah Heritage Hospice. It has access to needed home health pediatric services, through a contract with Brookside Home Health. “Angel Watch” operates three innovative programs for children. The “Early Intervention Program” focuses on early, pre-natal diagnosis, when a fetus may be assessed as having such malformations that may result in a stillbirth or death as a neonate. Emotional support is given to parents and the family in their home during this pre-birth period. The support continues through delivery and post-birth, regardless of the outcome. The “Children’s Program” includes any child diagnosed, pre or post birth with a terminal illness, and addresses the physical, emotional, and spiritual needs of the child and family. The third program is called “Children of the Adult Patient” and helps children who have

lost a significant adult in their lives work through their grief. Child life therapists visit children in their home and help them accomplish this work through play therapy. All of these services are provided regardless of ability to pay. Services are available 24 hours a day by trained individuals in the home, as needed.

G. Community Support Organizations

1. **Family Voices of Utah** is part of a national, grassroots clearinghouse for information and education concerning the health care of children with special health needs. Family Voices of Utah operates as a distinct project affiliated with the Utah Parent Center, a parent-run private, nonprofit organization that also serves as the federally funded Parent Training and Information Center (under IDEA - the Individuals with Disabilities Education Act). The relationship between the Utah Parent Center and Family Voices represents a tremendous, mutually beneficial partnership in addressing the needs of families and providers statewide. Family Voices of Utah also provides technical assistance and coordination for Family Voices states in Region VIII (Utah, Montana, Colorado, South Dakota, North Dakota and Wyoming).

Family Voices of Utah is actively involved in many activities including policy making, systems change, participating in state, regional and national advisory councils and boards by sharing experiences and expertise of families of children with special health care needs.

2. **Rocky Mountain Candlelighters for Childhood Cancer** is a non-profit organization whose mission is to be a resource for families with a child who has or has had cancer, by providing patient advocacy, educational, emotional, and practical support. The organization serves over 900 families who live in Utah, Wyoming, Nevada, Idaho, and Colorado whose child is or has been treated at Primary Children's Medical Center.
3. **The Sharing Place**, located in Salt Lake City, provides a safe and caring environment where children, teens, and their families who are grieving the death of a loved one may share their feelings while healing themselves. Located in a restored bungalow style home, The Sharing Place offers grieving families connections with others who have experienced their feelings and an opportunity to work through grieving issues with peer support. Children, teen and adult groups are structured to deal with needs specific to each. Art, music and other activities are also utilized to ease the sharing process. Efforts are made to facilitate adults' understanding of the grieving process in children and adults.
4. **Intermountain Ronald McDonald House** - While many communities benefit from the "home away from home" offered by Ronald McDonald Houses®, Salt Lake City's house serves a larger population than most. Located downtown, the Salt Lake City Ronald McDonald House® serves three major hospitals treating children: Primary Children's Medical Center, Intermountain Shriners' Hospital for Children and the University of Utah Hospital. These hospitals and Intermountain Ronald McDonald House® serve families from the multi-state Intermountain region that is the largest geographic region served by any children's facility in the United States. For a nominal nightly fee, families traveling

50 miles or more from the Salt Lake City area can have the conveniences of a private room and bath, a common kitchen area, laundry and recreational areas. Thirty families may be served in the main Ronald McDonald House® facility. A new facility, opened in 2002, provides accommodations for up to fifteen families and children who are immuno-compromised and in Salt Lake City for treatment.

5. **The Intermountain Shriner's Hospital** is a 40-bed pediatric orthopedic hospital providing comprehensive orthopedic care to children at no charge. The hospital is one of the 22 Shriner's Hospitals throughout North America. Serving children with a variety of routine and complex orthopedic problems, Shriner's offers both inpatient treatment and outpatient clinics. Among the orthopedic problems most commonly treated at the Intermountain Shriner's Hospital include spina bifida/myelodysplasia, metabolic bone disease and skeletal growth abnormalities. Intermountain Shriner's Hospital focuses on a multi-disciplinary family centered approach to treating children with orthopedic issues and their families.
6. **The Partnership to Improve End-of-Life Care in Utah** is a coalition of institutions and individuals who are committed to combining their efforts and expertise toward improving care for persons nearing the end-of life and their families. The Partnership directs its work toward the public, health care professionals, and policymakers. Health Insight formed and sponsored the Partnership about three years ago through a Robert Wood Johnson Foundation grant. The vision of the Partnership is that all Utahns facing life-threatening illness and their families expect and receive competent, responsive, and compassionate end-of-life care. As such, they inform and engage the public, provide education and training for health professionals, serve as a resource for policymakers, and facilitate, collaborate, and function as a clearing-house for data collection on end-of-life care in Utah. Some of the products and services offered through the Partnership include a web site: www.carefordying.org for resource guides, outreach to religious organizations, pain management education for physicians, *etcetera*.

During the past year, due in part to the Utah PACC program, the Partnership has increased its focus on palliative care for children. Written and electronic materials produced by the Partnership now include information about pediatric palliative care. Future collaborative efforts between the Partnership and the Promoting HOPE program are aimed at increasing the substance, quality, and accessibility of information available to the community about resources for children and families in need of pediatric palliative care.

Section IV Needs Assessment, Public Input, Feasibility

“If I can be completely honest from my heart...I needed someone...someone who was [a] source of information. Someone with a humongous heart who would say, ‘I understand... you are not yourself.’” -Focus group participant

The Promoting HOPE Advisory Council, through the support of the PACC® grant from the Centers for Medicare and Medicaid Services and Children’s Hospice International has worked diligently during the past two years to develop a plan that will address the needs of the target population. As such, the planning effort included a number of efforts to assess the issues, the needs, service gaps, the capacity and the size of the potential users of the service. We used a variety of methods to obtain a better understanding of the individual and community need, including focus groups, surveys, questionnaires, interviews, and data analysis. Even though the Advisory Council includes representatives from a wide variety of groups who have an interest in the target population, we also extended opportunities to the public and other groups and individuals to learn about the project and to participate in the design and development of the plan. These opportunities included a public forum, presentations at meetings of various related organizations, television interviews, creation of a video, articles in newsletters, personal interviews and other contacts with community leaders and families.

A. Estimating the Size of the Target Population

We employed a variety of methods to determine the size of the potential population of Utah children with life-threatening illness who might benefit from the Promoting HOPE program. These methods include compiling a list of ICD-9 diagnostic codes that are related to life-threatening conditions, an analysis of death certificate data, a literature search including national data, surveys of specialty clinics, Utah disease prevalence rates, consultation with medical experts, an analysis of Utah hospital discharge data and pediatric home health and hospice utilization data, as well as a comprehensive analysis of Medicaid and HMO claims data. A detailed explanation for this process is described in Section VI B, page 41.

Estimating the size of the potential target population has been difficult at best, even with the multiple methods used. These estimates range from 600 to 750 to 2,100 children in Utah who may have a life-threatening condition, or will benefit from palliative care. (See Table IV-1A-1C). The lower estimate is based on a recent survey of pediatric specialists at the clinics of Primary Children’s Medical Center. The high estimate is based on annual Utah hospital discharge data, which may include multiple discharges for the same person. The middle estimate is an extrapolation of Medicaid claims data to the Utah population of children, assuming about 30 percent of children with a life-threatening diagnosis are on Medicaid. Since we intend to open the program to all children in Utah after the first year of the program, not just children currently covered by Medicaid, this estimate is very important. We have chosen the middle estimate of 750 children, and have estimated that only about half the group will enroll because (1) the scope of services is designed to assist families who care for their child at home; (2) a majority of the children in the perinatal group will die shortly after birth; and (3) the family of a child who is not covered by Medicaid or CHIP will have to pay a fee for the home-based

services. See Table VII –1), page 45 for an explanation of the services.)

**Table IV - 1A: Estimating the Size of the Promoting HOPE Target Population:
Demographics**

Descriptor	United States	Utah <i>[About 1% of US child population]</i>	Utah Medicaid <i>[Between 18-30% of Utah child population]</i>
Total population <i>(Source)</i>	281,421,906 <i>(US 2000 Census)</i>	2,233,169 <i>(US 2000 Census)</i>	221,686 (unduplicated) <i>(FY 2000 DHCF)</i>
Population of children 0-18	72,325,430 <i>(US 2000 Census)</i>	719,080 <i>(US 2000 Census)</i>	(Ages 0-21) 130,000 <i>(416 report 1999)</i>
Percent of population under 18-21	(Under 18) 25.7% <i>(US 2000 Census)</i>	(Under 18) 32.2% <i>(US 2000 Census)</i>	(Under 21) 58.6%
Percent of population in urban areas in rural areas		76% 24% <i>(2000 census)</i>	(Under 21) 67% (Under 21) 33% <i>(Utah Medicaid)</i>
Persons per household	2.63 <i>(US 1990 Census)</i>	3.15 <i>(US 2000 Census)</i>	
Median household income	\$34,076 <i>(1995 model-based estimate)</i>	\$35,160 <i>(1995 model-based estimate)</i>	Varies, but most are under 100% of poverty which is \$14,600 for a 3-person family (2001)
Percent of children below poverty (\$14,600 per 3 person household in 2001)	20.8%. <i>(1995 model-based estimate)</i>	10.5% <i>(1995 model-based estimate)</i>	
Percent population non-white	24.9% <i>(US 2000 Census)</i>	10.8% <i>(US 2000 Census)</i>	35.1% <i>(FY98 DHCF)</i>
Children without health insurance	14.9% <i>(1996 US Census Brief)</i>	6.5% <i>(2000 Utah Child Health Survey, UDOH)</i>	

**Table IV - 1B: Estimating the Size of the Promoting HOPE Target Population:
Child Deaths and Children with Chronic Conditions**

Descriptor	United States	Utah	Utah Medicaid
Children who die annually	53,000 <i>(Am. Acad. Of Pediatrics)</i>	491 <i>(1990-1999 Utah vital statistics)</i>	88 - 147 <i>(Extrapolated from Utah vital statistics)</i>
Estimated no. of children who die annually with a designated life-threatening diagnosis (Utah Medicaid/Vital Statistics)	18,204 <i>(Extrapolated from Utah data)</i>	181 <i>(1990-1999 average, Utah vital statistics)</i>	55 <i>(MMIS and UT vital statistics data)</i>
Estimated number of children who die annually with complex chronic conditions (Feudtner)	15,000 <i>(Feudtner, et. al- excludes most perinatal diagnoses)</i>	151 <i>(Extrapolated from Feudtner data)</i>	27 - 45 <i>(Extrapolated from Feudtner data)</i>
Estimated number of children within 6 months of death with complex chronic conditions (point in time)	5000 <i>(Feudtner, et. al)</i>	50 <i>(Extrapolated from Feudtner data)</i>	9 -12 <i>(Extrapolated from Feudtner data)</i>
Estimated number of children (0-17) with severe chronic illness who would benefit from palliative care. (NACHRI)	1,374,183 <i>(NACHRI estimates 1.9% of population)</i>	13,661 <i>(Extrapolated from NACHRI data)</i>	2,470- 4,098 <i>(Extrapolated from NACHRI data)</i>
Estimated number of children with a severe chronic condition <i>(GAO report)</i>	1,000,000 (.01383) <i>(GAO report 1989 & Children's Hospice International)</i>	10,000 <i>(Extrapolated from GAO report)</i>	1,800 - 3,000 <i>(Extrapolated from GAO report)</i>
Estimated number of children with a designated ICD-9 diagnostic code indicating a life-threatening condition. <i>(Utah Medicaid)</i>	1,223,746 <i>(Extrapolated from Medicaid FFS claims data)</i>	12,168 <i>(Extrapolated from Medicaid FFS claims data)</i>	2,200 (.01692) <i>(Based on Utah Medicaid FFS claims CY 2000)</i>
Prevalence of Various Serious Conditions Among Utah Children <i>(C. Norlin Prevalence Rates)</i>	1,114, 300 <i>(Extrapolated from national/Utah prevalence rates)</i>	11,143 <i>(Based on national and Utah prevalence rates)</i>	2,014 <i>(Extrapolated from national/Utah prevalence rates)</i>
Estimated number of children with chronic life-limiting conditions. ChiPPs	446,000 <i>(ChiPPs paper, March 2001)</i>	4,460 <i>(Extrapolated from ChiPPs paper)</i>	802 – 1,380 <i>(Extrapolated from ChiPPs paper)</i>

**Table IV - 1C: Estimating the Size of the Promoting HOPE Target Population:
Children with Life-Threatening Conditions**

Descriptor	United States	Utah	Utah Medicaid
Annual hospital discharge cases for children with a designated life-threatening diagnosis (<i>Utah 1999 Hospital Discharges</i>)	218,200 <i>(Extrapolated from Utah hospital discharge data)</i>	2,182 <i>(Based on Utah 1999 hospital discharge cases)</i>	393 – 654 <i>(Extrapolated from Utah hospital discharge data)</i>
Estimated number of children who would benefit from palliative care (daily census) (<i>ChiPPs</i>)	6000-8000 <i>(ChiPPs paper, March 2001)</i>	600-800 <i>(Extrapolated from ChiPPs paper)</i>	108 – 180 <i>(Extrapolated from ChiPPs paper)</i>
Children who live with chronic life-limiting conditions (UK)	72,235 <i>(UK estimates 10:10,000)</i>	719 <i>(Extrapolated from UK estimate)</i>	130 - 215 <i>(Extrapolated from UK estimate)</i>
Children not expected to survive childhood because of a life-threatening condition. (Utah Pediatric Specialists)	60,266 <i>(Extrapolated from Utah survey)</i>	600 (.000834) <i>(Based on survey of Utah pediatric specialists)</i>	108 - 180 <i>(Extrapolated from Utah survey)</i>
Children not expected to survive childhood because of a life-threatening condition as defined in the Utah Algorithm (Includes tech waiver)	139,081-75,869 <i>(Extrapolated from Utah Medicaid claims & Utah Algorithm)</i>	750 - 1,383 <i>(Extrapolated from Utah Medicaid claims & Utah Algorithm)</i>	250 <i>(Based on Utah Medicaid claims; CY2000 based on Utah Algorithm)</i>

B. Focus Groups and Interviews with Parents

To obtain a better understanding of the needs of Utah families, we conducted focus groups and interviews in the spring of 2001 with parents of children who had died of a life-threatening condition. We believed the information gleaned from these conversations would help us design a program responsive to the needs of such children and families.

We mailed 143 invitations to parents whose child had died in the period between 1997 and 2000, of whom 42 indicated a willingness to participate in a focus group or interview. We held three focus groups with 25 parents in two different locations and telephone interviews with another 18 parents. The discussion guide for both the focus groups and interviews concentrated on the parent's experience with respect to the phases of the child's illness from diagnosis to treatment to death and touched on their experience with providers, insurance, community support and the effect on the child and family. We also asked the participants to discuss the positive and negative aspects of their experience and rank the availability and adequacy of a "wish list of support service." (See Appendix B for the survey form.) One hundred percent of the group we spoke to had health insurance coverage for their child. About 62 percent had private health insurance, another 21 percent had Medicaid plus private insurance, and 14 percent relied solely on Medicaid. About 40 percent of the children died in the hospital and 60 percent died at home.

About 89 percent of the children were over the age of one when they died.

The focus groups identified a number of themes similar to those in other focus groups conducted by Primary Children's Medical Center in Utah in 1999 and by other PACC programs in Kentucky, and Florida.

- Parents had difficulty obtaining information about the disease, treatment options, available resources, and what to expect during the course of the illness. Parents felt their expertise with respect to their child was discounted or ignored. They often felt left out of the decision-making process.
- Many indicated a lack or absence of care coordination or management within the hospital, among caregivers, or across systems. Many families juggled the care coordination on their own, without much help or expert information.
- Parents expressed dissatisfaction when hospital admissions were delayed because of the lack of beds, or when the child's length of stay was extended because procedures were not done in a timely manner, or because of inadequate coverage for home health care. Inconsistent hospital practice that left parents confused regarding what they could expect was also a problem for some families. Others complained of a lack of expertise or equipment in regional hospital that forced transfer or admission to the tertiary children's hospital.
- Parents who cared for their child at home usually had no comprehension of how this would impact the life and routine of the entire family. Inadequate coverage for home health services, demands on parents to perform complex medical tasks for which they had little training, juggling the responsibilities for the child while managing routine responsibilities of a job, other children, the household, coordinating medical care, and dealing with insurance companies, left parents feeling frustrated and overwhelmed. Although a few of these families qualified for respite support through the two Medicaid HCBS waiver, most did not qualify because the child did not meet the diagnostic or functional categories for these waiver programs. Other children in the family often felt neglected during the course of the sibling's illness and some displayed behavioral problems.
- Pain and symptom control was spotty at best. Some parents indicated they were not trained to adequately recognize signs of pain, even though they were charged with managing the frequency of the administration of pain medication.
- Information about what to expect at the time of death was uneven, particularly for those whose child died at home. Many received bereavement and grief counseling in their communities, but most felt that though the attempts were well meaning, the person counseling was inexperienced in matters pertaining to the death of a child. The withdrawal of support personnel at the time of the child's death magnified the loss.
- Most of the families were strapped financially because health insurance coverage was not comprehensive or they were forced to give up a job to care for the child, or because costs related to the child's illness such as frequent trips to the hospital, child care for siblings, or

needed medical supplies or care were not covered by insurance. All families expressed frustration regarding the inordinate amount of time they had to spend sorting out insurance claims at the same time they were trying to manage and deal with their child's illness and death.

A full report of the results of the Focus Groups and interviews "Conversations with Parents who Lost a Child to a Life-Threatening Illness" is included in Appendix C.

C. Public Forum – Public Decision Makers

On November 9, 2001, about 11 months into the planning process, the Division of Health Care Financing, in collaboration with the agencies on the Promoting HOPE Advisory Council, held an all-day public forum "A Day of HOPE," in Salt Lake City. The forum was held to accomplish the following objectives: (1) inform the public and professionals about the PACC® model and palliative care; (2) present the concept and design of the Utah Promoting HOPE plan to address the needs; and (3) obtain public input on the concept and design of the plan.

We sent invitations to more than 500 persons representing parents and parent advocates, home health or hospice agencies, state and local agencies, hospitals, insurance carriers, chaplains, *etcetera*. About 110 persons attended the forum and those who registered identified themselves as follows:

Home health or hospice care	37
State agency	28
Parents	14
Hospital	13
Medicaid HMO	04
Other	14
TOTAL	110

The program included presentations by Ann Armstrong-Dailey and Paul Brenner of Children's Hospice International who spoke about the PACC® model. We also showed a video we had created specifically for the program, "Seeking Hope When a Child Dies," based on conversations with parents who had participated in the focus groups and interviews to highlight the issues faced by families with a child with a life-threatening diagnosis. We invited decision-makers to share their reactions to the video and respond to questions. These included, the director of the Department of Health, the CEO and the medical director of the Children's Hospital, a legislator, the CEO of a major health insurance company, the director of the state facility licensing bureau, and an attorney specializing in health matters. We also presented the concept and design of the proposed Utah Promoting HOPE plan. The breakout sessions in the afternoon were held to allow all forum participants to ask questions and comment on the proposed plan.

The forum was extremely successful in reaching a wide audience and giving us constructive feedback on the design of the proposed program. We reviewed and discussed the comments from the panelists and the participants in the break out sessions and formed five work groups around the major issues of Eligibility and Enrollment; Services, Provider Standards and Reimbursement;

Evaluation, and Funding. The work groups review the issues, developed recommendations, and a plan to address the issues. These have since been incorporated into the design and implementation plan that is set forth in this application.

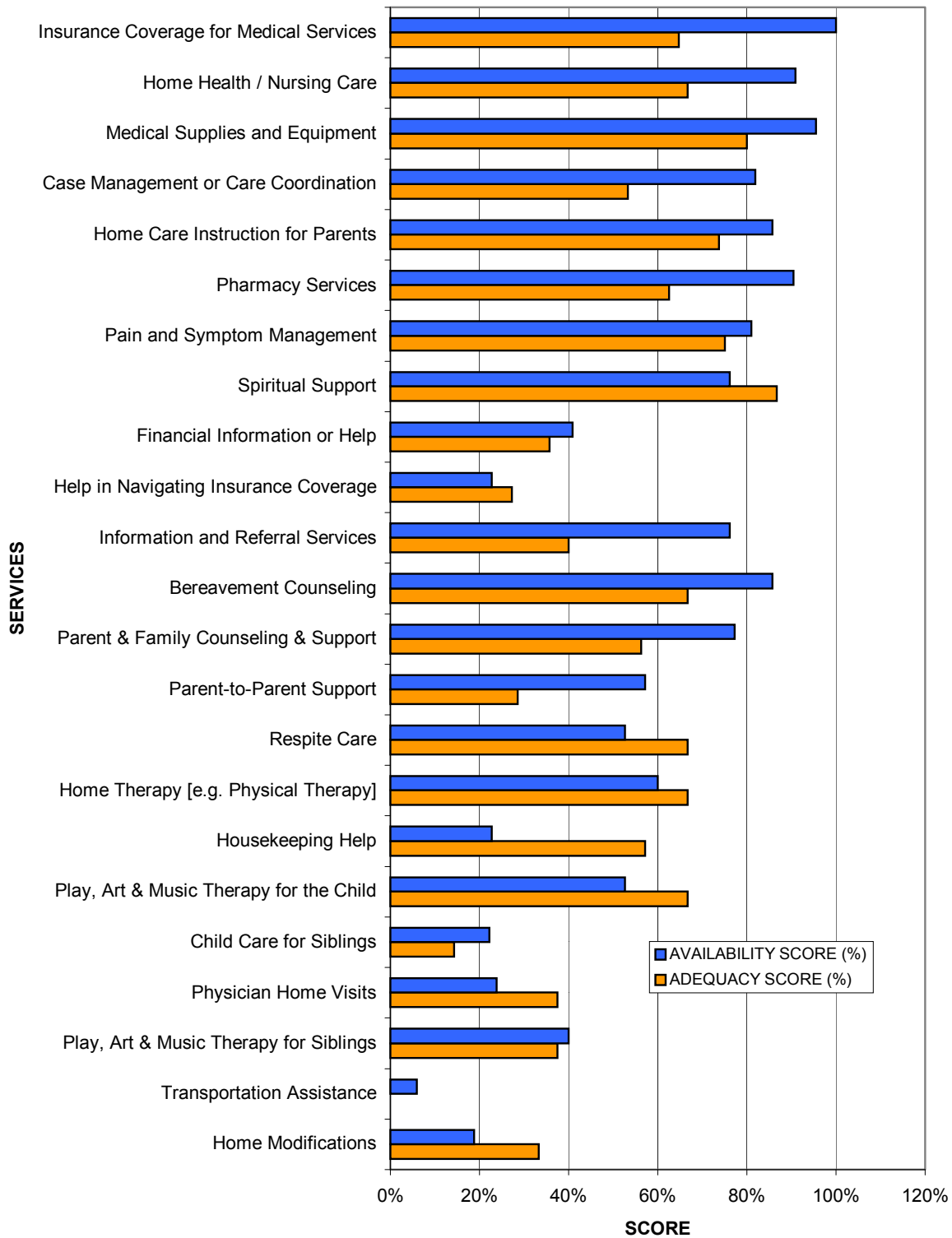
D. Wish List of Support Services - Parents

To identify specific service needs, we surveyed the 40 parents who participated in the focus groups and interviews and asked them to rank various support services to indicate their availability and adequacy (Table IV –2 and Figure IV-1). We used the results in designing the package of services that will be offered to the target population. We also intend to use the survey results to establish a baseline for the evaluation of the Promoting HOPE program after implementation.

Table IV – 2: Ranking of Services By Parents

Tier	Rank	Service	Availability Score (%)	Adequacy Score (%)
1	1	Insurance Coverage for Medical Services	100%	65%
2	2	Home Health / Nursing Care	91%	67%
	3	Medical Supplies and Equipment	95%	80%
	4	Case Management or Care Coordination	82%	53%
	5	Home Care Instruction for Parents	86%	74%
3	6	Pharmacy Services	90%	63%
	7	Pain and Symptom Management	81%	75%
	8	Spiritual Support	76%	87%
	9	Financial Information or Help	41%	36%
	10	Help in Navigating Insurance Coverage	23%	27%
	11	Information and Referral Services	76%	40%
	12	Bereavement Counseling	86%	67%
	13	Parent & Family Counseling & Support	77%	56%
	14	Parent-to-Parent Support	57%	29%
	15	Respite Care	53%	67%
	16	Home Therapy [e.g. Physical Therapy]	60%	67%
4	17	Housekeeping Help	23%	57%
	18	Play, Art & Music Therapy for the Child	53%	67%
	19	Child Care for Siblings	22%	14%
	20	Physician Home Visits	24%	38%
	21	Play, Art & Music Therapy for Siblings	40%	38%
	22	Transportation Assistance	6%	0%
	23	Home Modifications	19%	33%

Figure IV - 1: Availability and Adequacy of Services Ranked by Importance



E. Assessment by Pediatricians

In conjunction with the “Medical Home Project,” administered through the Title V agency, and the Partnership to Improve End-of-Life Care in Utah, we attempted to gauge the knowledge and interest of pediatricians in managing the care of children with a life-threatening illness in their practice. We posed five questions to pediatricians at the Intermountain Pediatric Society Conference (AAP Utah Chapter) in June 2001. The majority of the 100 pediatricians, who responded to the survey, indicated they would like more information on palliative care and resources for their patients with a terminal illness. Furthermore, less than half felt comfortable managing the terminal phase of the patient’s illness and a slightly higher percentage felt comfortable communicating with the specialist on behalf of their patient. These results indicate a gap between parental expectations and pediatrician’s knowledge and willingness to be involved in managing the terminal phase of the child’s illness. These results also emphasize the need to make education an important part of the Promoting HOPE project.

Table IV – 3: Results of Survey of Pediatricians- June 2001, Salt Lake City, Utah

Question	Agree or Strongly Agree
1. I feel comfortable managing the terminal phase of my patient's illness:	40%
2. I would benefit from additional training/education in pain and in the management of pain and other symptoms during the terminal phase of illness.	79%
3. I would find it helpful to have more information about existing resources available to support families with a child with a life-threatening illness.	90%
4. I am comfortable coordinating the communication between specialists and my patient when complex end-of-life issues arise.	58%
5. My patients with terminal illness and their families need better access to support services than they are generally able to access under our current system of health care delivery and financing.	66%

F. Legislative, Administrative and State Budget Considerations - Funding Entities

In 2002, Utah, like many other states, experienced a massive budget shortfall. In several special sessions, the legislature worked to trim spending to make up for a \$138 million dollar shortfall in the FY2002 budget and an anticipated shortfall of \$173 million shortfall in the budget for FY2003. State agencies including the Medicaid agency were forced to make program and administrative budget cuts.

Beginning a new Medicaid program in the midst of budget cuts poses a significant challenge. However, there continues to be a commitment to this project, in part because of the compassion for children who are dying and for their parents. The hypothesis that we can expand support services to the target population while maintaining budget neutrality has also helped garner support to implement the program. As a result of the budget problems, we will phase in coverage for the expanded group of eligibles. The phase-in period will allow us to test the hypothesis on the target population covered under the current Medicaid population, before we expand to a new group of eligibles. The positions needed to administer the program (See

Section V) will be phased in as the number of enrollees increase. We will use a combination of state and foundation funds for the state match for the administrative portion of the program for the first two years. This will give us time to obtain more permanent state funds for administration of the program, as the Utah economy and budget situation improve. If the program is implemented in July 2003, we anticipate that a portion of the PACC grant from Children's Hospice International will be used to fund one of the needed administrative positions. Primary Children's Medical Center has also committed to absorbing some of the outreach functions among their current staff. Current staff in the Division of Health Care Financing will carry out other administrative functions. We expect to create a new Care Coordinator Position, with existing funds.

G. CHIP

The Director of the CHIP program has agreed to expand the CHIP benefit package for children who meet the medical criteria for the "Promoting HOPE" program, so children who qualify for CHIP will also have access to similar services in the "Promoting HOPE" benefit package. This expansion will probably be phased in during the second year of the Promoting HOPE program. During year one, we will work with CHIP administrators to gain federal approval and draft the needed formal agreements to make this a reality.

H. Pediatric Standards for Home Health and Hospice

We have been meeting with the Director of the Bureau of Health Facility Licensing in the Utah Department of Health in February 2002 to discuss the feasibility of amending the current rules for home health and hospice agencies to include more explicit standards for pediatric care, to help improve the quality of care for all children in Utah served by a home health or hospice agency. We are currently in negotiation with the Bureau and the Health Facility Committee, responsible for establishing health facility licensing standards. In conjunction with the Bureau, we have drafted suggested revisions, which will be considered by the Committee during the next few months. We anticipate these standards will be in place before the implementation of the program and will allow agencies a period of time to meet all the credentialing requirements.

I. Training and Resource Development

To increase knowledge of palliative care and the availability of trained professionals and volunteers in the community who can support children with life-threatening conditions in a home setting, we are working collaboratively with the Partnership to Improve End-of-Life Care in Utah, Primary Children's Medical Center, current home health pediatric experts, the School of Nursing, and Children's Hospice International to determine how best to meet the training needs for professionals and volunteers who can serve children with serious medical conditions. Since we expect to make training and experience in pediatric care a standard in the amended rules for agencies that wish to serve children, we will try to meet this need through a collaborative effort with the agencies indicated above. We are exploring foundation grants as a possible source of funding for these efforts.

J. Letters of Support

The following have sent letters of support (see Appendix D) for the proposed Promoting HOPE for Utah Children Program:

Name / Title	Organization
Carolyn Kasteler**, RN, Director	Angel Watch, Utah Heritage Hospice
Vera Frances Tait, MD, Bureau Director	Children with Special Health Care Needs, Utah Department of Health
Dale F. Evans, RN, PhD, Vice President	Community Nursing Services
Gina Pola-Money* **, Director	Family Voices of Utah
Jeff Schunk, MD, FAAP, President	Intermountain Pediatric Society (American Academy of Pediatrics, Utah Chapter)
Kristine Ferguson, MSW, Director of Child and Family Services	Intermountain Shriners Hospitals for Children
Michelle Larsen, Director of Program Services	March of Dimes Utah Chapter1
Joseph R. Horton, CEO	Primary Children's Medical Center
Helen Rollins, RN, Coordinator	Spirit of Caring, Intermountain Health Care, LDS Hospital
Lynne M. Kerr*, MD, PhD, Assistant Professor	University of Utah Medical Center, Departments of Pediatrics and Neurology
Nancy Ballou, RN, President	Utah Hospice Organization

*Currently parents a child with a life-threatening illness.

**Bereaved parent.

K. Public Notice

We are in the process of publishing a public notice in the State Bulletin, to inform the public about this application. The State Bulletin is available online and is distributed to all public libraries in the State of Utah. Copies of the proposal will be made available for public review and comment during February 2003. We have also made two presentations at the public meeting of the Medical Care Advisory Committee that advises on Medicaid policy. The last presentation was made in November 2002.

Section V

Program Administration

“The insurance company had a hospice, but only for adults. The hospice didn’t know how to deal with children dying. They didn’t know how to deal with parents who wanted to have their child at home to make the dying experience okay.” -Focus group participant

A. Overview of the Proposed Administration

The Division of Health Care Financing, (DHCF) which is the single state Medicaid agency, in the Utah Department of Health will be the entity responsible for administering the proposed 1115 research and demonstration project, Promoting HOPE for Utah Children. (See Section V-B below for detailed staffing and job descriptions.)

The Division will contract with the Bureau for Children with Special Health Care Needs (CSHCN) within the Division of Family and Community Health, in the Utah Department of Health to act as the Care Coordinator for all children enrolled in the Promoting HOPE program. CSHCN is a Bureau within the Title V agency in Utah with responsibility for outreach and direct care for children with special health care needs (See page 13 for more information about CSHCN) In addition, we will contract with Primary Children’s Medical Center (PCMC) to conduct outreach and coordination activities for the program. This will be a sole source contract because 70-80 percent of the children who will be candidates for the program are diagnosed at PCMC, the quaternary children’s hospital in Utah. (See page 14 for more information about PCMC).

We anticipate that in the first year of the program, two half-time positions will be needed in the Division of Health Care Financing to administer the Promoting HOPE program. One position will be the Insurance Navigator, and the other will serve as the Program Administrator. Current staff in the Bureau of Managed Health Care, Bureau of Eligibility Services, and Medicaid claims will absorb other duties described below, or work will be reallocated among staff in those Bureaus to allow the assumption of the duties described below. The Division of Health Care Financing will contract with the Division of Community Health and Primary Children’s Medical Center for the creation of the new positions of Care Coordinator and Outreach Coordinator, respectively. The Program Administrator will monitor these contracts to ensure the responsibilities are carried out in a coordinated manner.

Thus, the Program Administrator, the Outreach Coordinator, the Care Coordinator, Eligibility Worker, and Insurance Navigator will form the core administrative team for the Promoting HOPE program (See Appendix E, Organization Chart). As the number of enrollees increase, we will add staff to meet the need.

The Advisory Council established to oversee the development of the Promoting HOPE program and the 1115 waiver will also continue to meet after the implementation of the program to maintain coordination, advise on program issues, and provide oversight. The membership of the Council will be expanded to include more parents and providers. This Council will help ensure

the program is operating in accordance with program goals and principles.

B. Staffing and Other Administrative Functions

1. Division of Health Care Financing, Utah Department of Health

a) Program Administrator - (new ½ FTE), Bureau of Managed Health Care

Qualifications - Master's degree in a health care, social work, communication, or related field plus at least two years related experience. Knowledge or experience in Medicaid or other large health care delivery system, parent advocacy, program evaluation, policy development. Ability to organize complex tasks, communicate effectively (orally and in writing), analyze data, evaluate programs, manage grants, deal effectively with the public.

Duties - Oversee all aspects of the Promoting HOPE program to ensure it is properly and efficiently administered and operated, specifically:

- Implement and maintain compliance with the approved 1115 requirements.
- Act as liaison to CMS and oversee the completion of all reports, *etcetera*.
- Manage grants.
- Recruit and enroll Promoting HOPE providers.
- Manage all related contracts, interagency, and provider agreements.
- Monitor the program and oversee quality assurance and evaluation activities.
- Coordinate with the Promoting HOPE team, including other DHCF staff and contract employees, and other agencies involved with the Promoting HOPE program.
- Track the number of enrollees, collections, expenditures.
- Staff Promoting HOPE Advisory Council.
- Recommend changes in policy, procedure for the program, and implement, based on oversight and input of the Promoting HOPE team and the Advisory Council.
- Troubleshoot system issues, edits, consumer and provider issues, complaints, data reports.

b) Eligibility Worker - (100-150 cases per FTE), Bureau of Eligibility Services

Qualifications - Medicaid eligibility or similar eligibility experience, or a bachelor's degree or a combination of education and related experience. Knowledge of program components of a large public health system; public relations as it relates to health service providers; effective interviewing principles, practices and techniques, service provider problems and concerns as they relate to public health. Ability to communicate effectively both orally and in writing; work under stress with conflicting priorities; deal effectively with program administrators in the private and public sectors; analyze and respond to service provider needs.

Duties - The eligibility worker will conduct eligibility assessments in accordance with Medicaid and the Promoting HOPE program, specifically:

- Coordinate with the Care Coordinator to enroll and dis-enroll children in accordance with program requirements.
- Assess the fees required for the program.
- Ensure family completes needed paperwork to maintain the child's eligibility for the program.
- Coordinate with the Insurance Navigator regarding coverage issues.

The eligibility worker, who will take on the duties for the Promoting HOPE program, will also have responsibility for determining eligibility for Home and Community-Based waiver for Technology Dependent Children and will be housed at the offices of the Bureau of Children with Special Health Care Needs, at the same site as the Care Coordinator. Eligibility determinations for individuals outside of the Salt Lake Area will also be coordinated through the designated Promoting HOPE eligibility worker.

c) Insurance Navigator - (120-180 cases per FTE) Bureau of Medicaid Operations

Qualifications - Experience in customer service and health insurance claims and benefits administration. Knowledge of Medicaid, health care and health insurance systems. Skill in negotiating, dealing with people, and organizing and managing information and data.

Duties - Assist families in navigating benefits with their insurance carrier, specifically:

- Assist families in understanding their health insurance benefits and rights (COBRA, CHIP, HIPAA, UCHIP, private coverage, *etcetera*.)
- Coordinate the Promoting HOPE package of benefits with the child's other health insurance coverage.
- Help families maintain current or other available insurance coverage for their child to maximize benefits.
- Collaborate with hospitals, pediatricians, home care and other providers in identifying and navigating insurance benefits.
- Act as a resource regarding insurance benefits to other health care professionals serving the child.
- Act as advocate or ombudsman regarding coverage issues and assist families in getting resolution, including explaining grievance and appeals process and referral to pro-bono counsel as needed and requested.
- Maintain a file of coverage benefits provided by the major insurance plans to assist the agency and family in negotiating flexing of benefits.
- Periodically review the explanation of benefits (EOB) statements to track patterns of coverage in the insurance industry. Report significant changes in benefits to decision makers who meet with insurance representatives.
- Coordinate with other members of the Promoting HOPE team.

d) Other DHCF Administrative Functions - In addition, other staff in the Division of Health Care Financing will absorb other administrative activities for the Promoting

HOPE program, that are required to operate and manage any Medicaid program, including claims payment, data and systems management, budgeting, distributing information and provider bulletins, provider, hearings, monitoring.

2. Division of Community and Family Health Services, Utah Department of Health

Care Coordinator – (60 cases per FTE) (Medical Professional; through interagency agreement with DHCF Medicaid agency) Bureau for Children with Special Health Care Needs

Qualifications - Licensed as a Registered Nurse, with at least one year of pediatric case management experience, knowledge of Medicaid and the health care system, skills in team building, negotiating, and organization.

Duties - Act as principal care coordinator for all children enrolled in the Promoting HOPE Program by linking with all entities that are or will be involved in the care of the child, specifically:

- Conduct assessments of the child and family to determine medical eligibility for the program and the need for palliative care in accordance with program requirements.
- Coordinate enrollment with the Eligibility Worker.
- Conduct the initial care coordination meeting with the family and other agencies in the development of a coordinated service plan.
- Authorize all needed Promoting HOPE services.
- Monitor the delivery of services to ensure services are coordinated in accordance with program standards.
- Develop referral protocols in conjunction with the Outreach Coordinator to ensure providers, hospitals, physicians, insurance carriers, not included in the protocol developed for PCMC and University Medical Center, refer clients and provide needed information to link families to the Promoting HOPE Program.
- Maintain open lines of communication with Promoting HOPE providers to address problems and ensure they have needed information, education, and training to deliver services in accordance with program standards.
- Coordinate with other members of the Promoting HOPE team.

3. Primary Children's Medical Center - (Children's Hospital)

Outreach Coordinator - (100 to 150 cases per FTE) will report to the Director of Family Support Services at Primary Children's Medical Center. The Medicaid Agency will contract with PCMC through a sole source contract for this position.

Qualifications: Bachelor's or Master's Degree; experienced in dealing with families with seriously ill children and health professionals; advocacy, and fund raising; knowledge of hospital systems, community resources and health care system; written and oral communication skills, negotiation and advocacy skills; ability to convey empathy and understanding.

Duties - Oversee all services in Package A (see ?? for description of services) - outreach, information, “goodie bags,” referrals and coordinate enrollment.

- Develop and implement a referral protocol among all clinics and departments at PCMC and the University of Utah to ensure families whose child is diagnosed with a life-threatening illness will have access to and obtain needed information in a consistent and sensitive manner.
- Help develop and maintain up-to-date information packets to be provided to all families referred to the program.
- Coordinate with the Children with Special Health Care Needs Webmaster to maintain the Promoting HOPE section of the website and to ensure the site and links reflect the information included in the parent information packets.
- Meet with each family referred to the program to inform them about the Promoting HOPE Program and provide information on needed community resources, or develop and monitor a uniform process using other hospital staff or parent support coordinators.
- Maintain the inventory of “goodie bags.”
- Coordinate with PCMC Foundation for funding to support the “supply of goodie bags” for all families referred to the program.
- Coordinate enrollment in the Promoting HOPE program with the Care Coordinator and Eligibility Worker, providers, including arranging the initial home visit.
- Serve as a liaison between Promoting HOPE Program, hospital administration, and other staff.

4. Consulting Contracts/Temporary Positions

In addition to the above positions, the Division of Health Care Financing may contract for the following consultation services:

- a) Early Intervention and Research Institute, Utah State University Evaluation Consultation Services; through agreement with another state agency.

The Division of Health Care Financing may extend its current contract with the Early Intervention Research Institute to validate the reliability of an instrument originally developed to measure caregiver burden for persons caring for an elderly person. This instrument is in the public domain. We plan to modify the instrument for parents caring for children who are ill and test the modified instrument during the first year of the program. Once the instrument is validated and normalized, we will use it to determine the level of the family’s need for the support services to be offered through the “Promoting HOPE Program.” We believe this instrument will provide base-line information regarding the level of family stress and may also be used to help the family determine their need for support services and enrollment in the program. This instrument will be particularly useful, if we have to limit enrollment because of budget considerations. (A copy of proposed instrument is in Appendix F.)

DCHF may also request consultation on methods of evaluating the quality of services

and measuring performance objectives of the “Promoting HOPE” program.

b) Education/Marketing Expert; temporary DHCF position.

Through the PACC planning grant DCHF hired an education/marketing expert in May 2002 on a temporary basis to coordinate compilation and development of the educational and resource materials that will be distributed to referral centers and in the packets for parents referred to the program. This person will also be responsible to coordinate with the Bureau of Children with Special Health Care Needs to make the same information available on their website, which will also serve as the website for the Promoting HOPE program. All materials should be developed and approved before the implementation of the program. We are also collaborating with Primary Children’s Medical Center on developing a comprehensive packet of information that will be distributed to all families whose child is diagnosed with a life-threatening condition.

c) Training and Resource Development for Community Providers, Volunteers, and Individuals Providing Spiritual Support who will serve the Target Population.

We have submitted the initial application for a Robert Wood Johnson, Local Initiatives Funding Partner’s Grant to help develop resources and develop methods to train home health/hospice, other professionals, and volunteers in the special needs of the pediatric population. Resources will also be developed in conjunction with other community-support organizations to better meet the needs of the target population in their communities. Training methods may include just-in-time, video, peer-training and remote training through the ed-net tele-health system. If funding for this training initiative is obtained, the Division of Health Care Financing will work in conjunction with the Advisory Council to develop a scope of work, objectives, qualifications, and a process to recruit a person or entity to carry out these functions, in accordance with the State of Utah procurement requirements.

5. Promoting HOPE Advisory Council

The function of the current Promoting HOPE Advisory Council will be changed from a planning and designing to functioning as the oversight body for the Promoting HOPE program. The Advisory Council’s role will be to ensure program goals are being met and that the program is operating in accordance with the program principles. In addition the Council will advise on policy issues and help ensure system coordination. As such, membership will be expanded to include more parents, and representatives of other agencies. A new leader will be selected for the Council and the Program Administrator and other Promoting HOPE administrative team members will staff the Council.

Section VI Eligibility

“Well, just try to find out how you get qualified for a Medicaid waiver. Nobody seems to know. Nobody will tell you. ‘If you make too much money, you don’t qualify for anything.’” -Focus group participant

A. Eligibility for the Promoting HOPE Program

We developed the medical eligibility criteria in accordance with PACC® principles to allow any child with a life-threatening condition to have access to the program from the time of diagnosis. In addition we were guided by the following principles in establishing eligibility criteria for the program:

- Criteria should be transparent, unambiguous, easily understood.
- Criteria should not result in hearings, protracted disputes, or waiting lists.
- Physicians should not be made the gatekeepers of financial benefits.
- Information about the program and the cost and benefits should be available, preferably at the point of diagnosis, to all families with a child with a life-threatening illness who live in Utah.
- Parents should make the decision to enroll based on an informed choice that allows them to weigh the cost and benefits.
- In keeping with the overall program principle “families must participate in the cost of care and services to the extent they are able.” Children of families who qualify for Medicaid or CHIP under the State Plan will not be charged fees, however the expanded group will be assessed a fee.

Rationale - The eligibility criteria were developed to increase the number of children with life-threatening illness and families who will have access to supportive services. Required insurance coverage and the fees for the support services for the expansion group are the elements that will help establish a budget neutral program, even as we increase the number of children and families who will qualify for the program. Since Medicaid is the payer of last resort, we believe that a major portion of the medical services for all enrollees will be paid by their insurance plans. Fees will help ensure the program is budget neutral in accordance with requirements for the Section 1115 research and demonstration model. However, we will establish fees for children whose family income and resources exceed current Medicaid State Plan requirements, based on a sliding fee schedule.

Piloting the program with current Medicaid eligible groups and phasing in the expanded population in higher income groups in Year Two, will give us the opportunity to fine tune the program including: testing the referral, admission and enrollment process, better understanding the needs of the target population and child and family preferences, improving our estimates of program and per capita costs. Furthermore it will give us additional time to determine what we can reasonably charge families in the expanded group, whose income exceeds Medicaid standards and who will be assessed a fee.

1. **Medical and Financial Eligibility Criteria For Package B Home-Based Supplemental Services** (See page 45 for a description of the benefits)

A child is eligible for the program if the child meets *both* medical and financial eligibility requirements. A *child* means a person from birth to age 18. If the child is enrolled before age 18, coverage will continue until the child's 22nd birthday.

a) Medical Criteria

- 1) The child has a life-threatening medical condition so serious it is unlikely the child will survive childhood, as determined by the treating physician; and
- 2) The treating physician annually certifies that the child continues to have a life-threatening medical condition; and
- 3) The family annually updates information on their financial status.

b) Financial Criteria

- 1) Year One - During Year One of the Section 1115 research and demonstration model program (proposed July 1, 2003 to June 30, 2004)
 - (a) The child is eligible for Medicaid under the aid categories in the approved Medicaid State Plan in effect during Year One of the demonstration; and
 - (b) The child is not enrolled in an approved Utah Medicaid home and community-based waiver program. A child who is enrolled in an approved Utah Medicaid home and community-based waiver program, and who meets the financial criteria in (a), above, may transfer to the Promoting HOPE program, if the medical and financial benefits are greater.
- 2) Subsequent Years - Proposed July 1, 2004 to June 30, 2008)
 - (a) The child is eligible for Medicaid under one of the aid categories in the approved Medicaid State Plan in effect during each subsequent year of the demonstration period and not simultaneously enrolled in an approved Utah Medicaid home and community-based waiver program; or
 - (b) The child would be eligible for Medicaid under the Medicaid State plan if s/he were in a medical institution, terminally ill, and eligible to receive hospice care in accordance with Section (1902) (a)(10)(A)(ii)(VII) of the Social Security Act. 4 and covered by other health insurance (excluding CHIP); or

4 The state will use institutional deeming rules which generally do not consider the parents' income and resources in determining the child's eligibility]; (See Waivers, Section XIV)

- (c) The child is not eligible for Medicaid under item (a) or (b) above, but is covered by other public or private health insurance (excluding CHIP), and the financially responsible parent or guardian signs an agreement to pay the assessed fee for Promoting HOPE supplemental services in accordance with a sliding fee schedule, based on the family's adjusted gross income reported on their latest individual or joint federal tax returns.

2. Extended Eligibility for the Family of a Child who Dies

If a child who is enrolled in the Promoting HOPE program dies during the enrollment period, the family will be eligible to receive counseling and bereavement services for eighteen months after the child's death, without the need for any other financial eligibility determination.

3. Presumptive Eligibility

There will be no presumptive eligibility for services, except that the administrative services in Package A - Outreach and Referral Services will be available to all children/families referred to the program. (See Section VII for description of the benefits.)

4. Retroactive Eligibility

There will be no retroactive eligibility. The date of eligibility for services in Package B is the date of application.

5. Differentiating Traditional Medicaid Eligibles from New and Expanded Group

The Division of Health Care Financing will work with the Department of Human Services, that currently administers the Medicaid eligibility system, to develop new aid categories to differentiate among the new groups who will be eligible for the Promoting HOPE program. (See Table VI-1)

6. Excluded Individuals

- a) HCBS Waiver** - Children covered under the home and community-based services (HCBS) waiver for technology-dependent/medically fragile children, or under the home and community-based services (HCBS) waiver for persons with developmental disability will be excluded from this program. However, these children and their families currently have access to a number of support services, such as respite care that will also be covered under the Promoting HOPE program. To ensure the children who have life-threatening conditions in these two programs will also be able to access other needed palliative and support services, these two HCBS waivers will be amended by the beginning of Year Two to ensure similar access to palliative care.

Table VI - 1: Groups Eligible for the Promoting HOPE Program

	Group	Year 1 1 July 2003 to 30 June 2004	Years 2-5 1 July 2004 to 30 June 2008	Fees
Eligible Under State Plan	Eligible under the Utah Medicaid State Plan	Yes	Yes	No
	Eligible under the proposed Hospice State Plan Amendment	No	Yes	No
	Eligible for HCBS Waivers under the Utah Medicaid State Plan	Only if they transfer to Promoting HOPE	Not needed since HCBS waiver will be amended to include similar services	No
Not Eligible Under State Plan	Eligible for Utah HCBS Waivers under special waiver eligibility rules, but not under the Utah Medicaid State Plan	Transfer may not be possible because child may not qualify under the State Plan	Not needed since HCBS waiver will be amended to include similar services	N/A
	Not in any of the above categories or CHIP- but (1) covered by other health insurance & (2) parent agrees to pay assessed fee	No	Yes	Yes
	Enrolled or eligible to enroll in the Utah CHIP Program	No	May receive similar benefits under enhanced CHIP services	N/A
	Uninsured	No	No	N/A

- b) Uninsured** - Private insurance, Medicaid, or CHIP covers about 96 percent of the Utah child population. The budget neutrality requirements of a Section 1115 research and demonstration model make it impossible to include the small group of uninsured children who meet medical criteria for the program. We had originally considered offering the family an opportunity to buy into the Medicaid program for their child, but the fee or premium required to ensure budget neutrality would be prohibitively expensive. As such, we have dropped this option. However, if such a family were referred to the Promoting HOPE program, they would be linked to the insurance navigator who would help them explore all other options that might be available to them. In turn, these children and families would also be referred to any organization that may provide charitable care and services.
- c) CHIP** - Federal statute prohibits enrollment in of a child in the CHIP program, if s/he meets the criteria for enrollment in the Medicaid program. Since our goal is to provide access to needed services for all Utah children with life-threatening conditions, we have reached an agreement with the administrators of the CHIP program in Utah. They will amend the CHIP plan in Year Two of the 1115 Research and Demonstration Program to add enhanced benefits, comparable to the services in Package B, for children who also meet the medical criteria for the Promoting Hope Program.

B. Identifying the Size of the Target Population

We have adopted a very broad definition of the target population in keeping with PACC® model that indicates many children with serious illnesses, not only those who are close to death, can benefit from coordinated and palliative care.

1. Methodology to Identify Potential Numbers in the Target Population

To identify the number of children in the target population currently covered by Medicaid and the expanded population, we started with a sample list of life-threatening ICD-9 (International Classification of Disease Codes - Ninth Edition) that was included in the initial PACC® grant application (See Appendix A-2). We refined the list as follows.

- a) **ICD-9 Codes and Child Deaths** - We tallied the number of children 0-18 who died in Utah between 1990 and 1998 with a diagnosis related to those in Appendix A-2).⁵ Based on Utah vital statistics data, approximately 500 children die in Utah each year, of which about 181 die annually of one of the designated life-threatening illnesses in Appendix C. Of this group, two-thirds are under age one. We refined our original table by removing any diagnoses for which there had been no child deaths in the 9-year period we examined.
- b) **Comparison with National Data** - We conducted a literature search and modified our table based on the literature⁶. Feudtner estimated the number of children in the U.S. with complex chronic conditions who might benefit from hospice care and supportive services. His analysis excluded premature births (which in Utah is the category for the largest number of deaths), but included children from birth to 24 years of age. According to Feudtner's estimates, 15,000 children die in the U.S. each year from complex chronic conditions. About one third or 5000 of these children are living within six months of the end of life at any point in time and would benefit from hospice and similar supportive services. See Table IV 1A-C), for other extrapolations to determine the potential size of the target population (Medicaid and Utah column)
- c) **First Run of Medicaid Claims** - Based on the modified list, we compiled a list of all children 0 to 21 for whom Medicaid paid a claim between CY 1995 and CY 2000 for a primary diagnosis of one or more of the life-threatening diagnosis codes on the modified list. We obtained the data from both Medicaid fee-for-service claims and from Medicaid contracting HMOs. We identified on average about 2000 children each year for whom Medicaid had a paid claim including one of the diagnoses on the refined list (See Appendix A-1). The large number of children thus identified indicated to us that diagnosis codes alone were insufficient to determine the severity of a condition and whether the condition was indeed life-threatening. We decided to take additional steps.
- d) **Deaths in the Medicaid Group** - From this group we compiled the social security numbers and birth dates of children for whom Medicaid had a paid fee-for-service or

5. Although our original plan was to include deaths for a 10-year period from 1990-2000, the Bureau of Vital Statistics in Utah converted to the ICD-10 classification for deaths in 2000 and the coding system is an alpha numeric system, for which there was no easy cross walk.

6. Feudtner, et al., Pediatrics Vol. 6/2001; Feudtner, Pediatrics 2000; Gay, Pediatric Annals 3/1997

HMO claim between CY 1997 and CY 2000. This list was run against Utah Vital Statistics Deaths database to determine which children had died subsequent to receiving a Medicaid service as of the run date of September 2001. We identified 213 children with a paid Medicaid claim and a designated life-threatening diagnosis [ICD-9 code] who had died during this four-year period, or on average, 53 children per year. Using similar ICD-9 diagnostic codes, our original analysis indicated that 180 Utah children die annually as a result of a life-threatening condition. These results suggest that a disproportionate number of children on Medicaid die from these life-threatening conditions. Medicaid covers only about 18% of the child population of Utah but these deaths indicate that 29% of deaths occur among Medicaid-covered children. (See Table IV 1-B)

- f) **Utah Hospital Discharge Data** - We also compiled information from statewide hospital discharge data to determine the number of hospital discharges for children under the age of 21 in CY 2000 with a life-threatening diagnosis. We found 2,182 hospital discharges for all such children. The data shows discharges, not unduplicated individuals. Although the hospital discharge data indicates that only 17 percent of the 373 of the 2182 discharges were paid for by Medicaid, this number is misleading since children on Medicaid who are also enrolled in an HMO are counted under the “Managed Care” Primary Payer category. (See Appendix G.)
- g) **Survey of Hospital Specialty Clinics** - Concurrently, we surveyed physician specialists at the University of Utah Medical Center and Primary Children’s Medical Center who serve and diagnose approximately 80 percent of the children in Utah with such illnesses. The survey asked them to “guesstimate” the number of children in their practice whom they expect not to survive beyond age 18. Since this group of specialists serve only about 80 percent of the child population, based on their responses, we estimated that at any time, approximately 600 - 800 Utah children suffer from an illness that will prevent their reaching adulthood. These figures indicate that for every child who dies of a life-threatening condition or illness, there may be three to four times as many who remain alive but are not likely to live beyond age 18. If the Utah Medicaid program covers about 18 percent of the child population, then we would expect that between 108- 144 children in the Medicaid program would be unlikely to survive childhood. However, if as the death data indicate, 29 percent of all deaths from life-threatening conditions occur among the Medicaid child population, then we would expect a disproportionate number of children with life-threatening conditions in the Medicaid program. This extrapolation from the specialists’ “guesstimates” would suggest that about 174 to 232 children in the Medicaid program have a life-threatening condition.
- h) **Utah Algorithm** - Based on the physician survey, we believed that the 2000 Medicaid children identified earlier by ICD-9 code alone (item d, above), was probably too large. We hoped we could arrive at a number closer to estimates in the physician survey (item g, above) to better delineate the group of children who would likely be in the target population. To this end, we consulted with a number of medical experts, including Utah physicians and nurse practitioners who were pediatric specialists in chronic disease, hematology/oncology, genetic disorders, cardiologist, neurology, nephrology, endocrine, gastroenterology, neonatology, *etcetera* to help us develop and algorithm that would allow

us to identify an appropriate group of children from Medicaid claims data.

- i) We asked the medical experts to narrow the range of diagnosis codes to those most likely to result in premature death and to identify other elements on a claim form, e.g., additional diagnoses, hospital admissions, utilization of other services, that would help indicate the severity of the condition. Their input was used in the creation of the Utah Algorithm. (See Appendix A3 and A4.)
- j) **Medicaid Claims Based on the Utah Algorithm** - This algorithm was first run manually against the Medicaid fee-for-service claims for CY 2000 in the Utah “data warehouse.” At the same time, a programmer developed an automated program to capture data for other years. The results of the manual run and the automated run were compared to correlate the results and identify and correct any errors or problems. The following data elements were compiled for each child age 0 to 21 who met the criteria for selection: the Medicaid ID number, social security number, county, age, and aid category. Medicaid expenditures for inpatient and outpatient hospital, nursing facility, home health, professional therapies, physician, pharmacy, medical supplies, medical transportation, and all others. The program also captured third-party payments for hospital care, premiums paid to an HMO, number of days in the hospital or nursing facility, and the number of days in that year the child was eligible for Medicaid. To this was added all HMO expenditures for each child and any Medicaid payment for buy-in clients. About 350 children were identified in CY 2000 who met the criteria. Of these, about 50 were enrolled in one of the two home and community-based waivers. This group was not included in the main study group as they will not be enrolled in the Promoting HOPE Program. However, we did a separate analysis of the HCBS group as a basis to project costs.
- k) **Refinement of the Utah Algorithm** - The corrected program was run against CY 1999 and CY2001, the other years for which data was available and complete. The HMO expenditures were added to this report for each child. Any child who did not have a hospital claim paid by Medicaid or the HMO in any of the three years (CY1999-2001) or whose home health, pharmacy, medical supply expenditures for the year were less than \$4500 was determined not to meet the severity criteria. This final list of 234 children in 1999, 241 children in 2000, and 241 in 2001 constitutes the group whose historical expenditures are used to establish Medicaid historical expenditures for the target population.
- l) The last step was to identify any child on the preliminary list and the final list who had died on or before September 2002, subsequent to receiving a Medicaid service. This group was included in the final list.

C. Estimate of the Potential Target Population

Based on the average of 239 cases we identified in Medicaid program for CY1999-2001 plus the average 60 children in the HCBS waivers, and our estimate that 29 percent of children with life-

threatening conditions are enrolled in Medicaid, we conclude there are about 1000 children in all income brackets who form the potential target population of children with life-threatening conditions.

Section VII Benefits

"I found I wasn't in a position to teach people what my problems were. I was dealing with too many other things-- important things. But if hospice was involved they could have come in and given us the support we really needed." -Focus group participant

A. General Design of Benefits Package

We designed a unique two-tier benefits package (see Table VII-1) to give all families in Utah whose child is diagnosed with a life-threatening illness access to essential information and holistic support services from the point of diagnosis until at least 18 months after the child's death, as needed. This design is based on the PACC® model, the Promoting HOPE program goals and principles, input received from families who participated in the focus groups and interviews, and from other interested individuals.

Package A- Outreach and Referral Services, which include information, referral, and an initial assessment, will be provided free-of-charge to any family whose child is diagnosed with a life-threatening condition and referred to the program, regardless of income or resource criteria. This information will allow the family to make an informed choice regarding their options and whether they wish to enroll in the "Promoting HOPE" program to receive Package B services.

Package B - Home-Based Supplemental Services include a variety of services that will supplement either the Utah Medicaid State Plan services or the child's health insurance benefits to assist the family in managing their child's care in a home setting. Primary Children's Medical Center, which serves about 80 percent of the children with life-threatening conditions, has a number of support programs that will support children and families who choose to continue receiving all their care in the hospital setting. There will be no additional cost for the services in Package B to the families of children who are eligible for Medicaid under a State Plan eligibility category. However, there will be a fee for the children in the expanded coverage group (see Section XI, page 98).

All services in Package A are considered an administrative activity whereas the services in Package B will be categorized for service funding under the Section 1115 research and demonstration model. If the family subsequently enrolls in the Promoting HOPE program to receive the services in Package B, the initial care assessment available through Package A will be considered a service activity under the Section 1115 research and demonstration proposal.

Although eligibility for services is based on the child's medical condition, the unit of care is the child and the family. As such, services such as respite care, bereavement counseling, expressive therapies etc, may also benefit other family members, including parents and siblings. The family is defined as the relatives and/or significant persons who provide physical, psychological, social, and spiritual support for the child.

Table VII - 1: Promoting HOPE for Utah Children - Proposed Service Package, Fees, and Access

	Charge and Funding	Access	Proposed Services
Package A	<ul style="list-style-type: none"> · No Charge - All referred families · Funded through a combination of federal, state, local, grants, community fund-raising, private donations, and insurance. 	<ul style="list-style-type: none"> · All families regardless of income and resources · Accessible at diagnosis and any point in the course of the disease. · Informed of services and costs of Package B so parent can make an informed choice. 	Information/Coordination/Referral <ul style="list-style-type: none"> · Support for Immediate Needs · Transportation Assistance · Information & Referral regarding <ul style="list-style-type: none"> Disease Financial help Other Resources · Assessment · Insurance Navigator · Referral Counseling/Parent Support
Package B	<ul style="list-style-type: none"> · No charge to the family with child eligible under the Medicaid State Plan · Fee will be assessed on expansion group, not eligible under the Medicaid State Plan. · Fee based on sliding scale and deductions for paid health insurance premiums. · Funded through a combination of federal, state, insurance, and fee to family. 	<ul style="list-style-type: none"> · Geared to family with some private insurance coverage who selects to care for child at home. · Supplements private insurance and Medicaid coverage. <p>Family Choice Plan allows family to select provider for respite (including relatives) who are paid through broker up to a monthly maximum.</p> <ul style="list-style-type: none"> · May also access all services in Package A · Mandatory enrollment in a Medicaid HMO will be waived for enrollees in the expansion group. 	Home-Based Supplemental [Supplements child's home health benefit] <ul style="list-style-type: none"> · Case Management · Plan of Care · Palliative Care Consultation · Nursing & Other Therapeutic & Palliative Care · Counseling & Expressive Therapies · Ancillary Support & Family Choice Support · Traditional Respite & Family Choice Respite · Medical Supplies & Equipment · Pharmacy · Transportation

B. Package A Benefits - Outreach and Referral

1. **Principles** - We will develop a well-publicized protocol in conjunction with the entities who have contact with a child who is diagnosed with a life-threatening illness to ensure that at any point of entry, whether it is PCMC, another hospital, a physician's office, clinic, or health plan. The family will be referred to the program, so they can receive needed information to determine if they wish to participate in the Promoting HOPE Program.

In developing the services in Package A, we were guided by the following principles and guidelines:

- Each family will receive needed information in a supportive, compassionate, and sensitive manner.
- Information will be tailored to the specific needs of the family and will include general information about the Promoting HOPE program, how to obtain more information about the disease, and other useful information regarding community resources.
- Because parents are overwhelmed when they receive the initial diagnosis, the information will be available in a variety of forms (oral, written, web site.) The same information may be presented on different occasions or meetings to ensure the family has the needed information.
- The protocol will empower and encourage the family to signal what and how much they want to know.
- Hope will be stressed and information on issues regarding death will be provided, as appropriate.
- The distribution information will be coordinated among all entities to ensure the information is up-to-date, accurate, and consistent.
- The packet of information will be developed jointly with community partners.
- Items or services in Package A, not eligible for funding under the Section 1115 research and demonstration proposal, will be funded through grants and donations.

2. **Standard Process** - Although the protocols for providing the information in Package A, may vary, based on the point of referral, the standard process that will be in place for those referred from PCMC, where we anticipate the largest number of referrals will proceed as follows:

- a) **Initial Contact:** Shortly after diagnosis of the life-threatening diagnosis, a trained individual (physician, nurse, parent volunteer, or other member of the care team) will inform the parent of various assistance available to them and how to access these:
 - 1) **Immediate Needs:** Telephone card, meal voucher, lodging voucher or Ronald McDonald house, overnight supplies, book or toy. (May be provided by parent volunteer, volunteer coordinator, or clinic staff.) (Funded with grants and donations.)
 - 2) **Disease Information:** Where to search for more information on the disease or condition (websites or links, referrals, library)
 - 3) **Financial and Community Resources:** Who to contact regarding (Insurance, Medicaid, SSI, Promoting HOPE Program, other resources.)
 - 4) **Parent Support Groups:** Names of volunteers or groups to contact.

b) **Second Contact:** If the family has not initiated contact with any of the above, based on the established protocol, the Promoting HOPE Outreach Coordinator, or the trained and designated individual based on the protocol, will contact the family to ensure the family has the information they need, expand or address any items from the initial contact, and offer the following. The family will be offered a comprehensive information packet, tailored to the nature of the child's disease, including the following:

- 1) Explain Promoting HOPE program - (Package B) and make an appointment for any needed follow-up.
- 2) Discuss eligibility for Medicaid, CHIP, Promoting HOPE and make an appointment for any needed follow-up.
- 3) Discuss supportive services available through the hospital, community, parent groups, *etc.*
- 4) Explain Care Coordination options. Offer home visit to do an initial assessment and make an appointment for any needed follow-up.
- 5) Explain the role of the Insurance Navigator and make an appointment for any needed follow-up.
- 6) Respond to other questions and concerns and follow-up any other questions, as needed.

c) **Third Contact:** A home visit or other assessment will be conducted by the "Promoting HOPE Care Coordinator, or designated member of the care team, only upon the parent's request. The purpose of the assessment will vary, based on the status of the child.

- 1) If the child will continue to be hospitalized the assessment will ensure the care team at the hospital is aware of the family strengths and needs in the development of the care plan. Family and other community resources will be discussed to ensure that family is able to maintain the quality of life of the child and family.
- 2) If the parent wishes to manage the care of the child independently, the purpose of the assessment will be to empower the family and provide tips, tools, and other information to help them manage their child's care effectively.
- 3) If home health or hospice will be involved, the assessment/visit will be made in conjunction with the home health or hospice agency case manager to ensure there is good understanding of the family's strengths and needs in making the transition from hospital to home care and how best to coordinate all aspects of care. This assessment will help the family decide whether they wish to apply to enroll in the Promoting HOPE program to receive the benefits in Package B.

C. Package B Benefits - Home-Based Supplemental Services

1. **Principles** - In developing the services in Package B, we were guided by the following principles:

- All decisions in the delivery of care and services should be made in the child's best interest.
- The dignity, privacy, desires, culture, and choice of the child and family must be honored and respected.
- To further continuity of care, services must be planned, interdisciplinary, coordinated, and integrated among the family and all care givers, regardless of setting.
- The service plan should be based on a comprehensive assessment of the child and family's need, tailored and sensitive to the child and family culture and choices, and updated as indicated by change in status of the child and family.
- Services should be developmentally appropriate, flexible, and sufficient in duration and scope to meet the needs of the child and family.
- The needs of siblings and other family members should be considered and addressed.
- Therapies and interventions that may realistically be expected to improve the child's quality of life should be accessible.
- Services should be provided in the most appropriate setting, based on the need and choice of the child and family.
- The number of caregivers that come into the home should be minimized to reduce disruption to the child and family.
- The family should have the option to select substitute caregivers while accepting responsibility for their training and oversight.
- Families must participate in the cost of care to the extent they are able.
- Services should supplement the child's primary health insurance coverage, to ensure all resources are utilized effectively.
- To ensure adequate personnel are available to deliver needed care and service, volunteers and other trained individuals should be utilized whenever possible.

Table VII - 2: Package B Scope of Service and Qualified Providers

Home-Based Supplemental Services	Qualified Providers or Agencies
Essential Services	
HOPE Case Management	Licensed home health/hospice agency with pediatric certification.
Plan of Care Development	
Core Services – Expanded Home Health Care	
Palliative Care Consultation	Licensed MD and palliative medicine specialist not employed by or under contract with the hospice/home health agency
Nursing and Other Therapeutic/Palliative Care	Licensed home health/hospice agency with pediatric certification
Counseling and Expressive Therapy	
Ancillary Support	
Family Choice Support	Employed by or under contract with Medicaid contracting fiscal agent.
Respite Care	
Traditional In-Home Respite	Licensed home health/hospice agency with pediatric certification.
Facility-Based Respite	Licensed nursing facility or free-standing hospice facility.
Family Choice Respite	Employed by parent and under contract with Medicaid contracting fiscal agent
Other Wrap-A-Round Services	
Medical Supplies and Equipment	Qualified Medicaid Provider
Pharmacy	
Transportation	

2. **Package B - Supplemental Home-Based Services.** The home-based services in Package B include an array of comprehensive, interdisciplinary services designed to help preserve the quality of life of the child and family throughout the illness and beyond (see Table VII-2). These services must be authorized through the plan of care and supplement the other medical services available through the child's primary insurance plan (including Medicaid). The essential and core services will be available from or through qualified Promoting HOPE providers. Other wrap-around services will be available from qualified Medicaid providers. The services in the Family Choice Plan will be available from a person selected by, trained, employed, and supervised by the family, who is also contract with a qualified Medicaid fiscal agent.

a) **Essential Services**

- 1) **HOPE Case Management** - means a continuous process of assessment, oversight, and coordination of care to ensure that needed care and services are delivered seamlessly, in accordance with the comprehensive care plan developed in conjunction with the family and an interdisciplinary team that addresses the medical, social, educational, psychological, and spiritual needs of the child and, by extension, the child's family.

Qualifications - RN or licensed social worker employed by a licensed home health/hospice agency with a pediatric certification.

Limitations: None

- 2) **Development of a Plan of Care** - conferencing by an interdisciplinary team in creating a comprehensive plan of care in conjunction with the family that addresses the medical, social, educational, psychological, and spiritual needs of the child and, by extension, the child's family. The interdisciplinary team will include at least the Case Manager, MD, RN or Social Worker (if the case manager is the RN, then Social Worker must also be included, or vice versa) and one other team member, based on the child's needs and the family's choice, and the parent. The Promoting HOPE Care Coordinator must authorize the Promoting HOPE services in the plan of care. There should be at least one home visit in connection with the development of the plan of care.

Qualifications: Interdisciplinary team members through the licensed home health/hospice agency.

Limitations: May bill for plan of care once every six months (but must update, as needed).

b) **Core Services**

- 1) **Palliative Care Consultation** - means a face-to-face or remote consultation (e.g., telemedicine or telephone) with a physician who is a palliative medicine specialist regarding pain and symptom management. The consultation may be initiated by a member of the interdisciplinary team or requested by the parent.

Qualifications: Licensed physician who is a palliative medicine specialist, not employed by or under contract with the home health/hospice agency.

Limitations: None

- 2) **Nursing and Other Therapeutic or Palliative Care** means a home visit or visit to another community-based setting by one of the qualified designated licensed medical professionals listed below to assess or address one or more of the identified care needs of the child in the plan of care. The purpose of the visit, includes but is not limited to:

- Assessment
- Pain and symptom management
- In-home skilled nursing
- In-home respiratory care
- Infusion therapy
- Physical therapy

- Occupational therapy
- Nutritional interventions
- Training and instructing a family member care giver (non-paid) in the proper use of equipment and the treatment regimen for the child so they may safely maintain the child in the home and community setting

Qualifications: Licensed Professionals including RN, LPN, Physical Therapist, Occupational Therapist, Respiratory Therapist, Dietician, or other licensed practitioner providing services in accordance with their scope of practice, employed by or under contract with the licensed home health/hospice agency.

Limitations: To supplement services covered through the Medicaid State Plan, or the child's other health insurance benefits in accordance with the approved plan of care. Number of visits based on plan of care.

- 3) **Counseling and Expressive Therapies** - means services provided to the child or a member of the family unit in the home or other community location to guide and help them cope with the illness and the related pain, stress, grief, or loss. Families' choices must be honored in the selection of the qualified individual or individuals who will provide counseling service. Bereavement counseling will be offered for up to eighteen months after the death of the child enrolled in the Promoting HOPE program. Counseling may be directed to an individual family member or the family unit.

Qualifications: Licensed RN, Licensed Social Worker, Chaplain (board certified or credentialed as an Associate Chaplain by the Association of Professional Chaplains (APC) or by the Association of Clinical Pastoral Education (ACPE), Bereavement Counselor, Expressive Therapists including (Music and Art Therapist, Child Life Specialist), or other therapist in accordance with the approved plan of care, providing services in accordance with their scope of practice, and employed by or under contract with the licensed home health or hospice agency.

Limitations: In accordance with the approved plan of care.

- 4) **Ancillary Support** - means a home visit by one of the qualified ancillary support team members to manage and alleviate the child's symptoms, or to provide personal care for the child, or to relieve the family caregiver by performing general household activities.

Qualifications: Certified Nurse Aide employed by or contract with the licensed home.

Limitations: Not to exceed 8 visits per month, and in accordance with the approved plan of care. Family Choice Support Services may substitute for Ancillary Support services.

5) Respite Care Services

- (a) **Traditional Respite Care** - means short-term services to substitute for the child's primary care giver during an absence or to provide relief for the primary care giver, in accordance with the plan of care (in-home or facility based). Services may be provided in the child's home, licensed nursing facility, licensed free-standing hospice facility, or the home of a family relative or friend, selected by the family that is safe and can accommodate the equipment needed to manage the care of the child.

Qualifications: for In-Home Respite, any member of the nursing or medical care team who has the skills necessary to provide the respite care, as determined by the interdisciplinary team in the approved plan of care. For Facility-Based Respite, any licensed nursing facility or licensed free-standing hospice in accordance with the approved plan of care.

Limitations: 16 hours per month. (Unused hours may be accumulated.)

- (b) **Family-Choice Respite or Family Choice Support** - (Substitute Option) This is an option that allows the family to select a surrogate, i.e., a person who is known and trusted by the child and family, to provide temporary relief for the primary care giver or during a temporary absence by performing the duties the primary care giver would ordinarily perform in the care needed for the child, including care of the child, the household, and other siblings. The care will be provided under the direction of the primary care giver in the family.

Qualifications: The person must have the necessary skills to provide the services, and the primary care giver must accept responsibility for training and oversight of the person selected. The person selected must also be under contract with the Medicaid contracted fiscal agent for the Promoting HOPE Program.

Limitations: Family Choice Respite is limited to 40 hours per month in accordance with the plan of care and in lieu of traditional respite care. Family Choice respite hours may be used in combination with traditional respite hours in accordance with the [Table VII-3](#). The care plan must stipulate the level of support that may be provided by the surrogate selected by the family caregiver to provide respite and support.

Family Choice Support is limited to 8 hours per month in accordance with the plan of care (in lieu of ancillary support)

Table VII – 3: Combining Respite Hours in the Traditional & Family Choice Option

Traditional	16	15	14	13	12	11	10	9	8	7	6	5	4	3	2	1	0
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Family Choice	0	2.5	5	7.5	10	12.5	15	17.5	20	22.5	25	27.5	30	32.5	35	37.5	40
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Other Wrap-A-Round Services

- (a) **Specialized Medical Equipment and Supplies** - means any specified standard medical device, control, appliance, or supply that is not otherwise covered by Medicaid or the child's health insurance that is needed to manage the child's pain and symptoms, ensure the child's safety, or enable the child to perform the activities of daily living.

Qualifications: Qualified Medicaid Provider of Medical Equipment and Supplies.

Limitations: \$1500 per year in accordance with the approved plan of care.

- (b) **Pharmacy** - means any prescribed drug or other pharmaceutical covered under the Utah Medicaid State Plan, not otherwise covered by the child's health insurance, that is therapeutic or necessary to manage the child's pain and symptoms.

Qualifications: Qualified Medicaid Pharmacy Provider.

Limitations: Must be prior authorized for children not eligible for Medicaid under the Utah State Plan.

- (c) **Transportation** - means transportation services covered under the Utah Medicaid State Plan or as an administrative service, not otherwise covered by the child's health insurance, that is necessary to transport the child to receive needed therapeutic or palliative care.

Qualifications: Qualified Medicaid Transportation Provider or in accordance with Medicaid policy for administrative transportation services.

Limitations: In accordance with approved plan of care.

Table VII – 4: Package B – Summary of Limitations

Package B - Home-Based Supplemental Services	Limitations
Essential Services	
HOPE Case Management	None
Plan of Care Development	One plan of care every 6 months
Core Services - Expanded Home Health	
Palliative Care Consultation	None
Nursing and Other Therapeutic/Palliative Care	Number of visits based on plan of care
Counseling and Expressive Therapy	Number based on plan of care
Ancillary Support/Family Choice Support	8 visits per month, based on plan of care
Respite Care	
Traditional In-Home Respite /Facility Based Respite	16 hours per month, but unused hours may be accumulated
Family Choice Respite (in lieu of traditional respite)	40 hours per month, but unused hours may be accumulated
Other Wrap-A-Round Services	
Medical Supplies and Equipment	\$1500 per year
Pharmacy	Prior authorized for children not eligible under the Medicaid State Plan.
Transportation	As delineated in the plan of care

D. Carve Out and Excluded Services

1. **State Plan Eligible Group.** This 1115 research and demonstration project will not affect the way Medicaid State Plan and 1915(b) or 1915(c) waiver services are currently delivered and paid for under the Medicaid program for children enrolled in the Promoting HOPE Program who are eligible for Medicaid under the State Plan.

Children enrolled in the Promoting HOPE program who are eligible for Medicaid under the Utah Medicaid State Plan, will receive all services not included in Package A and B, as stipulated through the approved Medicaid State Plan or through any approved 1915(b) waiver. For example, if a child lives along the Wasatch Front, and is enrolled in an HMO, the child will receive all his/her services including home health and hospice care through the HMO. The provider may then bill the Promoting HOPE program for any of the additional benefits in Package B that are not covered under the Medicaid HMO contract. Mental Health services, with the exception of the counseling and bereavement services provided through the Promoting HOPE program, will continue to be accessible to State Plan Eligibles through the Prepaid Mental Health Plan or the State Plan, as applicable.

2. **Expansion Population Group.** This group of children, who will be enrolled in the Promoting HOPE Program in Year 2, will be eligible only for the designated services in Package A and Package B. They will not be eligible to receive any other Medicaid State Plan or 1915 (b) service. Since eligibility for the Promoting HOPE program is predicated on the child having another form of health insurance coverage, these children will have access to primary medical care through their insurance plan and the array of therapeutic,

palliative care, and support services available through the Promoting HOPE program. The Expansion Group will be made up of two groups: (1) Hospice State Plan Group who would be eligible for Medicaid under a proposed Hospice State Plan Amendment and (2) Non-Hospice Group would not be eligible for Medicaid under this option. For details on the waivers requested for this group, See Section XIV, pages 120-121. (See Also Table VI-1, page 39.)

3. **EPSDT Services.** This 1115 research and demonstration project, will not affect the way the EPSDT program currently operates for children eligible for Medicaid under the Utah State Plan. These children will have access to EPSDT services through any enrolled provider. As under current rules, the family may petition for any medically necessary services (not included in the scope of the Promoting HOPE program) that is not covered under the Medicaid State Plan.

E. Fees

We will charge a monthly fee based on a sliding fee schedule for the non-hospice expansion population group only. The fee will be based on gross family income and family size. We may allow deductions for out-of-pocket premiums for health insurance. (See Section XI, Table XI-18.)

Table VII - 5: Differences in Eligibility and Access to Services by Category of Eligibility for Children in the Promoting HOPE Program

	Traditional Medicaid	Expanded Group	
	Medicaid State Plan Eligible Group	Eligible Based on Proposed Hospice State Plan Group	Other Expanded Group
Life-threatening condition	Yes	Yes	Yes
Expected life expectancy	Up to age 18	Less than one year	Up to age 18
Must meet institutional admission criteria	No	Yes	No
Must have other insurance coverage	No	Yes	Yes
Parent's income counted to determine child's eligibility	Yes	No	No
Enrollment fee	No	No	Yes
Mandatory HMO enrollment if child lives in urban area	Yes	No	No
May access all Medicaid and Promoting HOPE services	Yes	Yes	Promoting HOPE scope of service <u>only</u>

Section VIII Delivery Network

“They were training us on machines at the hospital that weren’t the machines that were showing up at home.” -Focus group participant

A. Overall Design of the Delivery Network

Promoting HOPE Package A and Package B services will be provided through a network of public and private programs and agencies. In general, services in Package A will be reimbursed as an administrative service (except for the assessment and care coordination that will be considered a service activity for children who subsequently become eligible for the program), whereas the services in Package B will be reimbursed on a fee-for-service basis, except for some portion of transportation services.

Table VIII – 1: Package A - Administrative Services

Agency	Administrative Services - Package A
Primary Children’s Medical Center	Outreach, Information and Referral
Division of Community and Family Health, Department of Health (DOH)	Assessment, Care Coordination and Outreach
Division of Health Care Financing, Eligibility Services, DO H	Enrollment
Division of and Health Care Financing, Eligibility Services, DOH	Insurance Navigation

The services in Package B- Home-Based Supplemental Services will be provided through a combination of qualified Promoting HOPE and regular Medicaid providers.

Table VIII – 2: Package B – Home-Based Supplemental Services

Agency	Services - Package B
Licensed home health/hospice agency with pediatric certification enrolled as Promoting HOPE providers.	Case Management, Plan of Care Development, Nursing and Other Therapeutic/Palliative Care, Counseling and Expressive Therapy, Ancillary Support, and Traditional Respite
Qualified Medicaid Fiscal Agency	Family Choice Respite and Family Choice Support
Licensed Medicaid Provider or Facility	Palliative Care Consultation, Medical Supplies and Equipment, Pharmacy, and Transportation
Volunteers	Expressive Therapy, Grief Counseling

Incentives will be included in the agreements with Promoting HOPE home health/ hospice participating agencies to encourage the use of volunteers, to provide art and music therapy and services similar services that will benefit the child and family. Since these agencies currently rely on donations through fundraisers and similar activities to support the services provided to seriously ill children, the reimbursement methodology will encourage ways to continue community involvement and maintenance of effort to serve all children in the community.

B. Package A - Delivery System. Since these services are primarily administrative in nature, a member of the Promoting HOPE Administrative Team will deliver these services. See Section V, Program Administration and Section VII “Standard Process” for the manner and who will provide the services in Package A.

We will enter into a sole-source contract with PCMC to deliver the outreach and referral services because the overwhelming majority of children with life-threatening illness are diagnosed at PCMC. Thus PCMC is in a unique position to outreach to the target population.

Since the Bureau of Children with Special Health Care Needs is another state agency within the Department of Health, the same umbrella agency as the single state Medicaid agency, no solicitation process is needed for the services they will provide.

C. Package B - Delivery System

The primary providers for the Promoting HOPE program will be licensed Home Health or Hospice Agencies with pediatric expertise. Currently there are three such agencies in Utah that have a pediatric focus in the delivery of home health or hospice services, but there may be others interested in enrolling as providers for the Promoting HOPE program.

1. Proposed Provider Qualifications

- a) **Essential Services and Core Services** in Package B must meet the following requirements to enroll as a Promoting HOPE Provider:
 - 1) Be licensed as a Medicare certified Home Health or Hospice Agency.
 - 2) Demonstrated staff training and experience in serving a pediatric population.
 - 3) Have the capacity to provide the full scope of designated Promoting HOPE services directly or through contract.
 - 4) Have policy, procedure, and the capacity to provide bereavement counseling to the family for up to eighteen months following the death of the child served in the Promoting HOPE program.
 - 5) Have policy, procedure, and the capacity to coordinate with the PCMC.
 - 6) Have an active volunteer program that includes assigned staff or volunteer to recruit and train volunteers.
 - 7) Be a non-profit agency or demonstrate a willingness to provide charitable care for children who do not meet qualifications for enrollment in the Promoting HOPE program, by the second year of the demonstration.

- 8) Have access to an ethics committee or a system that can assist a parent, staff, or attending physician in making ethical decisions and providing advice on situations of an ethical nature.
- 9) Demonstrate a willingness to work with the families who select their own caregiver for respite or family support services under the Family Choice Option.
- 10) Have the capability to use telemedicine or other remote methods of consultation.
- 11) Designate the boundaries of geographic area to be served.
- 12) Demonstrate capacity to conduct specified Promoting HOPE satisfaction surveys.

To be enrolled in the Promoting HOPE program, a provider will be required to demonstrate that it can meet and will comply with the above requirements. As part of the program evaluation, the provider's compliance will be evaluated periodically. (See Section X – Evaluation and Quality Assurance and page 28 – Pediatric Standards

- b) **Fiscal Agent For the Family Choice Option** - Medicaid will contract with a fiscal agency that has demonstrated experience and the capacity to:
 - 1) Conduct background checks of the person selected by the family as the surrogate caregiver.
 - 2) Provide appropriate information to instruct the primary care giver who hires the surrogate to ensure the maintenance of accurate time sheets, *etc.*
 - 3) Generate payroll checks in a timely and accurate manner in compliance with all federal and state regulations pertaining to “domestic service” workers, including withholding and filing state and federal taxes, *etc.*
 - 4) Maintain accurate accounting and information systems necessary to invoice and track support funds and expenditures to the state.
 - 5) Generate and distribute IRS Wage and tax statements and related documentation in accordance with regulations.
 - 6) Maintain customer service mechanism to respond to worker, family, *etc.*
 - 7) Manage disaster recovery program to restore software and master files, *etc.*

It should be noted that the Family Choice Option must be selected by the primary care giver and must be authorized in the plan of care including the number of hours of care. Once the family has selected the surrogate caregiver, the person must undergo a background check by the fiscal agent. If successful, the primary care giver will be the employer of record and the primary care giver will be responsible to train the individual

to provide the designated care in the absence of the primary care giver. If this option is selected, Promoting HOPE will provide detailed information to help the family make appropriate choices, and the fiscal agent will provide them with needed information to manage time sheets, and other communication between the worker, the employer and the fiscal agent. (See Appendix H for examples of type of information that will be provided to the primary care giver by Promoting HOPE.)

2. Capacity - Estimated Number of Needed Providers

We project an average monthly enrollment of 67 cases in year one and 129 in year two (see Table XI –9). At present there are about 5 home health or hospice providers who have the capacity to serve children with life-threatening illnesses and who will likely qualify as Promoting HOPE providers by the effective date of the program. These five entities would be able to manage the caseload in the first two years. We are confident that we can recruit and train other providers in each subsequent year to handle the anticipated increase in caseload.

3. Provider Recruitment

We will notify all currently licensed home health and hospice agencies in Utah to inform them of the Promoting HOPE program and the qualifications for participation in the program. We expect to hold an information meeting in January 2003, for those interested in becoming Promoting HOPE providers. We will ask them to complete and application for participation in the program. The Promoting HOPE Advisory Council, will determine if they meet the requirements. If the requirements are met, the provider will be enrolled in the program after signing a Medicaid Provider Agreement.

Based on the need, we will repeat this process in subsequent years to ensure we have an adequate pool of providers to meet the needs of Promoting HOPE enrollees.

4. Reimbursement and Coding

All services in Package B will be reimbursed on a fee-for-service basis. Reimbursement of Promoting HOPE services to either home health or hospice agency will be on a fee-for-service basis. The rates will be in line with current rates to home health agencies for similar services. Table VIII-3 indicates only estimated not actual reimbursement rates. The rate schedule and the appropriate HIPPA codes will be finalized before implementation.

Table VIII – 3: Estimated Package B Reimbursement Rates

Package B - Supplemental Home-Based Service	Unit	Rate
HOPE Case Management	15 minute units aggregated to one hour	to be developed
Plan of Care Development - Interdisciplinary Team of at least 4 designated persons	plan of care	\$ 250.00 (estimated)
Palliative Care Consultation	brief, lengthy CPT	CPT pricing
Nursing and Other Therapeutic/Palliative Care	per visit	home health pricing
Counseling and Expressive Therapies	per visit	to be developed
Ancillary Support	per visit	\$36.00
Family Choice Support	per visit ??	\$15.00
Traditional In-Home Respite	per hour	\$40.00
Facility Respite	reduced nursing facility rate	
Family Choice Respite	per hour	\$16.00
Medical Equipment and Supplies	per Medicaid fee schedule	
Pharmacy	per Medicaid fee schedule	
Transportation	per Medicaid fee schedule	

5. Payment Process

Since all services will be reimbursed on a fee-for-service basis, providers will submit their claims through the regular Medicaid claims system. Thus all current controls in the Medicaid claim system to avoid duplicate payments, *etcetera*. will apply to Promoting HOPE services. We will be able to track payments and expenditures for the Promoting HOPE program through the MMIS. (See Section XII, Systems Support). We will also assure compliance with HIPPA coding requirements.

Section IX Access

“Choice really tapered down when it came to pain control.” -Focus group participant

As described in the previous section (See page 58), we will recruit an adequate number of providers to meet the need.

We believe the outreach and enrollment process, described in (Section VII -B),will be an effective method of reaching potential enrollees. The Outreach and Care Coordinator will also develop protocols to ensure that children who are served in clinics, physician offices, and hospitals outside of Primary Children’s Medical Center or the University Hospital will be referred to the program. Detailed information packets will be available to the family of all children referred to the program. The content of these packets is currently in development. We are working with the educational department at Primary Children’s Medical Center in the development and distribution of all materials to ensure that information is accurate, up-to-date, and not duplicative. (See Appendix H - 2 for a list of the proposed educational materials). We will also make the material in the packet available in Spanish. The Care Coordinator and Outreach Coordinator will also provide families with a list of the home health and hospice providers who are enrolled as Promoting HOPE providers and serve their geographic area, so they can select a provider.

Disenrollment Policy. The child may be disenrolled from the Promoting HOPE on the basis of any of the following events:

1. The family no longer wishes to participate in the program and voluntarily disenrolls.
2. The child’s condition is cured, or in the annual re-certification, the physician indicates the child is likely to survive childhood.
3. The child loses eligibility for Medicaid and the family does not wish to pay the assessed fee to continue participation in the Promoting HOPE program.
4. The family refuses to pay the assessed fees in accordance with the signed agreement.
5. The child dies (coverage for counseling services will extend for an 18-month period after the child’s death for other family members).
6. The child moves out of the State of Utah.
7. The family does not maintain primary health insurance coverage for the child, or no longer wishes to accept services from participating Promoting HOPE providers.
8. The child no longer meets other eligibility criteria for the Promoting HOPE program.

Section X

Evaluation and Quality Assurance

“I had to be my child’s advocate. I had to learn to be her advocate and learn all I could and not be afraid to speak up for what I felt was best for her. I know of several incidents when I did speak up, and it extended her life.” -Focus group participant

A. Purpose

The purpose of the evaluation plan is to establish the parameters by which the program can be measured in keeping with the Promoting HOPE and PACC® (Program of All Inclusive Care for Children with Life-Threatening Conditions) goals and principles. The quality assurance plan describes the basic methods that will be employed to ensure the health, safety and welfare of the clients in the program. The two plans complement each other and are designed to use limited evaluation resources economically and efficiently. Early identification of the data elements, tools and methods of collection, and process is essential to ensure appropriate resource allocation and implementation. The evaluation should give all stakeholders, including funding entities, administrators, providers, and clients the information they need to determine if the program is meeting expectations and is accountable. More importantly, the evaluation and quality assurance process and results will enable administrators, providers, and others to identify problems timely and make needed changes to improve program performance, based on documented evidence.

B. Evaluation Plan Development

The draft evaluation plan for the Promoting HOPE program was developed under the auspices of the Promoting HOPE Advisory Council, in the spring of 2002, more than one year prior to the planned implementation date of the program. A subcommittee of the Promoting HOPE Advisory Council developed the general outline of the plan during a one-day retreat. After determining what questions stakeholders (funding entities, administrators, providers, clients) might pose to judge whether the program is operating successfully and achieving positive results, we grouped these questions with the appropriate program goals. We then rephrased the questions into outcome goals and developed indicators based on information already collected at baseline or based on information we expect to collect from clients, providers, and others, as the program unfolds. Whenever possible, we used indicators similar to those suggested by Children’s Hospice International as common indicators to evaluate PACC® programs in all states. Members of the Advisory Council, a research consultant, and quality assurance surveyor also reviewed the plan. Although, the scope of the plan is comprehensive in scope, we may make further changes once the program is implemented.

C. Guidelines for Implementing the Evaluation Plan

To ensure the evaluation plan is in accord with the program that is finally approved, its administrative structure, funding and resources, the Promoting HOPE Administrator will be responsible to conduct a review all elements of the plan and make needed modifications before implementation of the plan. Future changes may also be needed to ensure consistency with standardized outcome measures established for this and other PACC® programs, to respond to

specific requests of stakeholders, and to develop more precise or sensitive indicators or collection methods. In the area of cost effectiveness and budget neutrality, we expect to collect and analyze more data to meet federal reporting requirements for the approved Section 1115 Research and Demonstration Model than is described in this evaluation plan.

The Enrollment and Family Survey should be developed during the first year of the demonstration program and ready for use by year two. The Promoting HOPE Administrator will be responsible to initiate the development of the needed instruments, method of administration, tabulation, and analysis. The survey should be developed collaboratively with the evaluation contractor, providers, other Promoting HOPE staff, and the Advisory Council. Although the plan delineates who is responsible for collecting the data and when, details regarding on the evaluation tools, methods, and survey process and time line will be added at a later date. The Promoting HOPE Administrator will be responsible to revise the plan and ensure it is carried out.

D. Outcomes Measures and Indicators

I	Goal: (Increase Access) Expand the support services available to all children in Utah diagnosed with a life-threatening illness.		
	Outcome/Process	Indicator	Source of Data
1	Families who are referred to the program and request information are contacted in a timely manner.	95% of families referred to the program who are surveyed report they were contacted or met with a Promoting HOPE representative, within four working days of the referral.	Enrollment Survey
2	Families who are referred to the program indicate the outreach information and process was helpful.	90% of families referred to the program, who are surveyed, indicate the outreach information process was effective & helpful in their decision-making process regarding their child's care.	Enrollment Survey
3	More children with life-threatening conditions receive palliative Promoting HOPE services than before the start of the program.	By the end of Year 2 of the demonstration, enrollment in the program will reach at least 200 (including Medicaid and new Eligibles.)	DHCF Promoting HOPE administrative enrollment data
4	Families receive palliative services and support services (Promoting HOPE services) earlier in the course of the child's disease than in the base year.	By Year 3, 50% of enrolled children, who die subsequently; will have been enrolled in the program for at least four months prior to their death.	DHCF base year and Promoting HOPE administrative enrollment data
5	Enrollment in the program in urban and rural areas of the state is proportional to the current population distribution.	By Year 3, the mix of children in the program from rural and urban areas will be similar to the mix in the base year (All Medicaid = Urban 59%; Rural 41%. Target Pop=Urban: 64%; Rural:36	DHCF administrative enrollment data
6	Enrollment fees alone do not pose a barrier to participation in the program.	By Year 3, of the families who wish to enroll and are required to pay a fee, 80% percent will enroll in the program.	DHCF administrative enrollment data

7	The eligibility and enrollment process is efficient	By year 2, 90% of enrollee applications will be processed within _ ? days.	DHCF enrollment data
8	The eligibility and enrollment process respects the privacy and dignity of the applicants.	95% of enrollees (parents), who are surveyed, report that workers respected their (a) privacy and (b) dignity during the outreach and enrollment process.	Enrollment Survey
9	Families and children receive all needed services identified in the plan of care.	By year 2, 90% of patient records, will show that child/families enrolled in the program receive the services identified in the plan of care.	Audits of provider records
10	Services needed by children and their families are readily available in their communities.	Families, who respond to the Wish List Survey, will indicate that services on the list are more readily available compared to the responses from respondents in the base year. Availability scores for services ranked below 60% will increase by 15%, scores above 60% but below 85% will increase by 10%.	Wish List - Family Survey (telephone or mail)
11	Services needed by children and families are adequate to the need (duration, scope, quality)	Families, who respond to the Wish List Survey, will indicate that services on the list are more readily available compared to the responses from respondents in the base year. Adequacy scores below 50% will increase by 15%, and scores above 50% but below 80% will increase by 10%.	Wish List - Family Survey (telephone or mail)
12	Community providers know how to make a referral to the program and are aware of the importance of early palliative care.	By Year 2, at least 75% of pediatricians surveyed at the annual Intermountain Pediatric Conference will indicate they have adequate knowledge of resources available to support families with a child with a life-threatening illness. (In the base year only 10% believed they had adequate knowledge of available resources).	Resurvey Intermountain Pediatric Association members at their annual meeting.
13	The medical home provider is involved in the child's care during the terminal phase.	By Year 3, at least 70% of pediatricians will indicate comfort in being involved in the care of their patient with a terminal condition	Resurvey Intermountain Pediatric Association at their annual meeting

II	Goal: (Cost Effectiveness) Maintain budget neutrality for federal dollars provided to the Utah Medicaid Program.		
	Outcome/Process	Indicator	Source of Data

1	More children with life-threatening illness are served in the Medicaid program using the same level of federal funding as in the years before the demonstration for a comparable group of children.	Average Medicaid expenditures to serve a child in the program will be less than the average Medicaid expenditures for a child in the same diagnostic category in the base year of the program.	Medicaid administrative claims data
2	Children in the program will spend fewer days in the hospital than a similar group of children before the demonstration.	The average number of hospital days of care per child in the demonstration will be reduced from the average during the base year.	Medicaid administrative claims data
3	Barriers to caring for children at home during the terminal phase of their illness are reduced.	By Year 5, more terminally ill children in the program will die at home than in the hospital. (Base Years: 60% died in hospital or institution and 40% died at home.)	Utah Vital Statistics data
4	The need for emergency room visits is reduced.	The average number of emergency room visits will be reduced for children in the program compared to a comparable group before the demonstration.	Medicaid administrative claims data.
5	Private insurance carriers maintain or exceed the level of coverage for covered services for children with life-threatening conditions.	Medicaid third party collections for children in the demonstration will be comparable to the third party collections for a comparable group of children before the demonstration.	Medicaid administrative claims data.
6	The community supports the Promoting HOPE program.	The Promoting HOPE program receives donations for items & services to meet the immediate needs (Pkg A) of families referred to the program. Home health and hospice providers are able to retain volunteers to work with terminally ill children for a longer period than before the demonstration.	A. Documentation by outreach coordinator. B. Provider documents & reports.

III	Goal: Improve the Coordination of Care, Access to, Use of Formal and Informal Community Supports . . .		
	Outcome/Process	Indicator	Source of Data

1	Families feel supported by the child's pediatrician and specialists throughout the illness.	85% of families in the program, who are surveyed, report the child's pediatrician and specialist were available to them throughout the course of the child's illness.	Family Survey
2	Parent- to- parent support is available to those who request such contact.	Parents who requested contact with other parents who have had a child with a similar condition, report receiving information needed to make the connection.	Family Survey
3	The transition of care from home to the hospital is seamless for the family and child.	(a) 90% of parents whose child is discharged from the hospital to the home report they were trained in needed procedures, and (b) the home health/hospice or medical supplier met the child's needs adequately and in a timely manner upon hospital discharge.	Family Survey
4.	Families can get help easily in a perceived emergency.	(a) At least 85% of families, who request an unscheduled provider visit, indicate the help they received was adequate and timely. (b) At least 95% of families, report they knew whom to contact in case of an emergency.	Family Survey
5.	When possible, parents who so choose, can use a family member or trusted friend to provide respite and related ancillary services.	At least 25 percent of the families enrolled in the program select respite/or ancillary care through the "family choice" option.	Medicaid administrative claims data
6.	Case Management services are available and beneficial to the families enrolled in the program.	(a) All plans of care/case management plans reviewed address all aspects of care (medical, social, spiritual, etc.) (b) There are no reports that a DNR order in one setting was not honored in another for children enrolled in the program.	Review of provider records. Review of provider incident reports
7.	Available community and family resources are explored and utilized when needed and appropriate.	All records reviewed indicate resources and support available from members of the family and family's community are explored in 95% of the cases.	Record review
8.	Services provided to the family or child by a volunteer are of value to the family.	At least 90% of the families surveyed, report satisfaction with services provided by volunteers.	Family survey

IV	Goal: Increase the Satisfaction and Stability of Families		
	Outcome/Process	Indicator	Source of Data

1	Parents have the information and support they need to make decisions about their child's care.	95% of parents surveyed report they have the (a) needed information and (b) support to make decisions regarding their child's care.	Family Survey
2.	Parents are involved in the care planning process.	All families surveyed, indicate they were included in the development of the plan of care.	Family Survey
3	The child and family receive needed services in accordance with the plan of care.	95 % of families surveyed indicate satisfaction with the services they received that were delineated in the plan of care.	Family Survey
4	The child's symptoms are well controlled during the last month of life.	85 % of families surveyed report that their child's symptoms were well controlled during the last month of life.	Family Survey
5	The care and support services available to the family enable the family to maintain the quality of life of the child and other family members during the course of the illness.	(a) 90% of family members surveyed, report satisfaction with the Promoting HOPE program. (b) Families surveyed, indicate other children in the family were included in child-life activities or other activities offered by the provider. (c) Families surveyed report few problems in getting time off from their employer to care for their ill child, when they so requested (collect for base line data on employer's practice for future planning and improvements). (e) The school district develops an IEP or 504 plan for a school-age child enrolled in the Promoting HOPE program when the school is notified of the child's condition.	Family Survey Family Survey Family Survey Family Survey School Survey/Provider Records
6	Family members are offered counseling and bereavement services.	(a) 90% of families are offered bereavement counseling for up to one year after the child's death. (b) By year 5, 80% families surveyed, who choose to obtain spiritual support and counseling from their faith-based community, report sensitivity to and understanding of their needs.	Provider Records Family Survey
7	Staff delivering care are competent and sensitive to the unique needs of each child and family	(a) Agency staff directly involved in the care of the pediatric patient comply with the required training requirements. (b) 95% of families surveyed report staff are sensitive to the needs of the patient and family.	Provider records Family Survey

E. Methods To Collect Data for Evaluation

A variety of methods and tools will be used to collect the information needed to conduct the evaluation of the Promoting HOPE program. These are described below including the item

number of the indicator to be measured.

Table X - 1: Methods To Collect Data for Evaluation

Collection Source/Tool	Indicator Number	Person or Entity Responsible	When
Enrollment and Outreach Records	I - 3, 4, 5, 6, 7 II - 6a	HOPE Administrator (DHCF) Outreach Coordinator (PCMC)	annually
Medicaid Claims Data - data warehouse, etc.	II - 1, 2, 4, 5 III - 5	HOPE Administrator (DHCF)	annually
Vital Statistics Data	II - 3, 6b III -	HOPE Administrator (DHCF)	annually
Provider Record Reviews	I - 9 II - 6b III - 7 IV- 6a, 7a	Care Coordinator (CSHCN)	start year 2
School Record Review	IV 5e	HOPE Administrator (DHCF)	start year 2
Intermountain Pediatric Survey	I - 12, 13	Outreach Coordinator (PCMC)	start year 4
Enrollment Survey	I -1, 2, 8	HOPE Administrator (DHCF) & Evaluation Contractor	start year 2
Family Survey	III - 1, 2, 3, 4, 8 IV - 1, 2, 3, 4, 5a, 5c, 5d, 6b, 7b	HOPE Administrator (DHCF) & Evaluation Contractor	start year 2
Wish-List Survey	I -10, 11	HOPE Administrator (DHCF) & Evaluation Contractor	start year 3

F. Quality Assurance Plan

Just as the Promoting HOPE Program builds upon and expands the services available to the child in the current health care delivery system, the Quality Assurance Plan builds upon and expands on the safeguards already in place to protect the health and welfare of the individuals who will be served by the program.

The Promoting HOPE program was designed with built-in safeguards for the protection of the child and family throughout the period of enrollment. Empowering the consumer (parent and family members) with information and education is at the core of the protection process. Individuals who have information and choice, know their rights and what to expect, know how and whom to address to get answers to their questions, know how to file a complaint when things do not go well, become their own advocates and keep the system and providers constantly in check in real time. The day-to-day oversight that is provided by informed and empowered consumers is the most effective method of ensuring that issues are addressed and resolved in a timely manner. Standards of care, credentialing, training, and administrative monitoring and oversight of providers are other key components of a quality assurance plan. A process to file, collect, review and address complaints and problems provides another feed back loop. Positive incentives also serve to bring about improvements. Together, these elements should result in a system responsive to users and open to correction to better serve the consumer. (See Figure,

1. Consumer Information and Education

The Outreach Coordinator or his/her representative will meet face-to-face with all parents of a child with a life-threatening condition referred to the program to inform them about the Promoting HOPE program and options. In addition, we will coordinate with key personnel at the hospital and other referral points to ensure the family receives written material and an oral explanation of disease process, treatment options, links to websites, care options, advance directives, tips to successfully advocate for their child, links to parent support groups, etc. among other items of information. When the child is enrolled in the program, information to help the family manage their child at home will be made available, including what to expect from providers, tips for resolving problems with home care providers, their physician, insurance companies, etc. Those who select to receive respite care through the family-choice option, will be given tips on how to select such providers. In addition, the family will receive information on how to file formal complaints and who to call when problems arise.

2. Advocacy

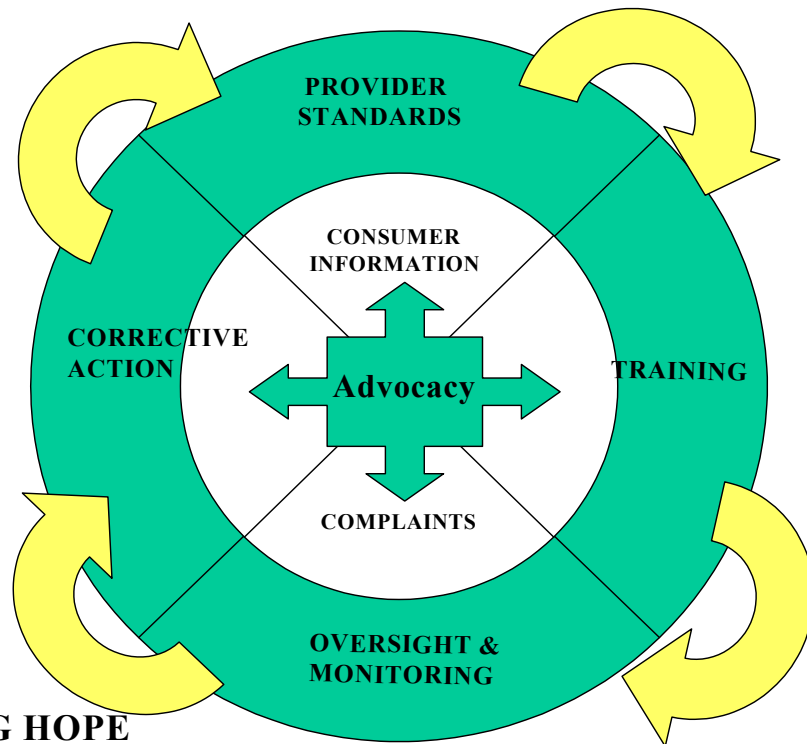
In most instances, parents who have information can advocate on behalf of their child. We will also facilitate links between the parent who requests contact with other parents who have a child with a similar condition or parent support groups. In our assessment process we learned that parent-to-parent contacts are the most helpful for many families who are learning about the health care system and how best to address issues related to their child's needs and connections. In addition, the Insurance Navigator and the Care Coordinator will also have an advocacy role on behalf of the child and family with insurance plans, providers, and other state agencies, respectively. The Care Coordinator will conduct or oversee the initial assessment of the child and family, authorize needed services, and periodically monitor the case, including direct contact with the family and the providers of care. If problems develop, the Care Coordinator will be in a position to help resolve a variety of issues related to the health and safety of the child, across the health care delivery system. The Care Coordinator is also responsible to coordinate referrals with community and regional hospitals, pediatricians, and other entities. In this function they also play an advocacy role on behalf of these children and families. The Outreach Coordinator who is stationed at the Children's Hospital will interface with all clinics, social work, and other hospital departments to advocate and ensure that systems and protocols are effective to address the needs of these children and families.

The Promoting HOPE Advisory Council also plays a role in advocacy.

One purpose of the periodic meetings with Council members, who represent parents, providers, state and local agencies, and others, is to ensure that all partners in the system are aware of and sensitive to issues that arise and can advocate and or bring about resolution of the issue within their own organization.

Other mechanisms to ensure effective advocacy include the requirement that home care

providers have access to ethics committees. We are also developing a palliative care consultation service that will be available to home care providers who need the help of experts in managing the pain and symptoms or other issues related to the care of the child. This access to outside help provides another means of advocacy for the child and family.



PROMOTING HOPE QUALITY ASSURANCE ELEMENTS

3. Standards

Program standards are based on Promoting HOPE and PACC® principles developed through extensive input of families, providers, and other experts. Providers must meet Medicaid or Promoting HOPE standards to become enrolled providers. These standards will be published in the form of a provider manual, before the implementation of the program. These will include the appropriate license and certification standards, when they exist. Home Health and Hospice providers will have to meet pediatric standards of care that should be in place before the implementation of the program. For Family-Choice respite providers, the person selected by the family must undergo a criminal background check and be linked with the approved Medicaid broker agency. The family will also be advised on how to ensure the individual selected demonstrates proficiency in performing the parent's tasks in his/her absence. The plan of care developed by an interdisciplinary team, including the parent, is another safeguard to assure there is a standard for the provision of services. Care standards require that the plan of care will be reviewed periodically and updated.

4. Training

Before program implementation we will hold training sessions for enrolled Promoting HOPE providers to inform them of the program requirements and standards. In addition we are seeking other sources of funds to develop materials and effective and efficient methods of helping providers, volunteers, and others who offer services to a family to improve their competence in serving children. We will collaborate with Children's Hospice International and any other local or national group that has developed standardized and accepted training materials and resources. Utah can then serve as a laboratory to test the training materials and methods to determine what works best.

5. Oversight and Monitoring

Oversight will be conducted on a number of levels. First, the Promoting HOPE Advisory Council will meet regularly to ensure the program is operating in accordance with the program plan. The Advisory Council may request in-depth reviews of problem areas and work with the Promoting HOPE administrative staff and their own organizations to develop effective solutions.

Participating Home Health and Hospice Providers are subject to periodic reviews by the Utah Department of Health Bureau of Facility Licensing and the surveyors in the Bureau of Medicare/Medicaid Certification. We will develop agreements and a process with these Bureaus to ensure they inform the Promoting HOPE Administrator of complaints or actions involving providers enrolled in the Promoting HOPE program. In addition, the Care Coordinator in conjunction with other designated staff will conduct periodic focused reviews of enrolled provider. The Care Giver Challenge Scale and other assessment instruments that we are developing will be administered periodically to help the care provider assess whether services are appropriately meeting the child and family need. Home Health and Hospice agencies currently have methods of surveying the satisfaction of their clientele. The results of these surveys are used to determine what changes are needed to improve the quality of care. We will support and encourage Promoting HOPE providers to use this information to augment the results of other reviews and surveys to determine what changes are needed to improve the quality of care.

In addition, we will coordinate our efforts with the administrator of the Utah Home and Community-Based Services (HCBS) Waiver Program for Medically Fragile Children, which is administered in the same bureau in the Division of Health Care Financing. The HCBS staff, allied agencies, and provider representatives are currently developing checklists and other methods to review providers of care. Since many of these providers will also become Promoting HOPE providers, we will coordinate review instruments, protocols, and results.

Primary Children's Medical Center, which is where many of the children in the program will receive initial care is already monitored and reviewed by a number of entities such as the Bureau of Licensing, JCAHO, NACHRI, among others. The hospital also has an internal quality assurance mechanism and various committees that addresses ethical as

well as quality of care issues.

The family will be responsible to oversee the Family Choice providers they select. We will provide tools, as will the Broker agency, to help families identify potential problems and issues including suggestions on how best to address these.

Home Health and Hospice agencies currently have methods of surveying the satisfaction of their clientele. The results of these surveys are used to determine what changes are needed to improve the quality of care. We will support and encourage Promoting HOPE providers to use this information to augment the results of other reviews and surveys to determine what changes are needed to improve the quality of care.

The Evaluation Plan includes a number of survey instruments that will be used to measure the effectiveness of the enrollment and care coordination process, as well as family satisfaction. The evaluation plan is another aspect of the oversight and monitoring that will take place.

6. Complaint, Grievance, and Correction

Parents and providers will be informed of the complaint process and grievance procedures. Complaints and their resolution will be logged and reviewed periodically, to determine if patterns emerge. This information, excluding protected information will be shared with the appropriate oversight entities. All oversight and review protocols will include a continuous feedback process to assure that problems and deficiencies are addressed in a timely manner.

The Promoting HOPE Advisory Council will review quality assurance problems and results of evaluation surveys, and reviews to determine needed program changes or procedures.

7. Incentives

Since positive approaches are often powerful motivators, we will also explore methods of improving the quality of care through incentives. The Promoting HOPE Advisory Council will also consider how best to put in place positive incentives to achieve system improvements.

G. Summary

In summary there are many safeguard protocols already in place, and others that will be developed, to ensure that children and families are well served and excellence is promoted.

Section XI Finance

“With some insurance companies worrying about the money becomes almost as big a problem as the illness itself.” -Focus group participant

This Section describes the methodology used to compile the Medicaid historical expenditure data to establish base year costs for the proposed Promoting HOPE program. The assumptions and method projecting total program and administrative costs for the program for a five-year period are also described. **The reader should be cautioned that calculations made from the tables in the hard copy or the WORD electronic version may show discrepancies due to rounding of data from the underlying EXCEL spreadsheets. The EXCEL spreadsheets are included separately in the electronic version of this document.**

A. Maintaining Budget Neutrality and Controlling Administrative Costs

The projections (see table XI-1) indicate that the Promoting HOPE program will be able to achieve budget neutrality while meeting the program goals of expanding support services available to the families of children with life-threatening conditions, increasing the number of children and their families who will have access to such services. These goals will be achieved by reducing the need for costly inpatient services, assisting families to better utilize their health insurance benefits, providing choice, and charging a nominal fee to certain groups.

Table XI-1: Five-Year Projected Enrollment and Program Savings

Year	Projected Enrollment	Without 1115 Demonstration	With 1115 Demonstration	Annual Savings	Cumulative Savings
1	120	\$9,760,605	\$9,718,253	\$42,352	
2	231	\$12,549,122	\$12,395,429	\$153,693	\$196,045
3	252	\$15,473,007	\$15,272,340	\$200,667	\$396,712
4	309	\$18,372,387	\$18,159,912	\$212,475	\$609,187
5	327	\$20,384,050	\$20,136,464	\$247,586	\$856,772

Table XI-2: Five-Year Projected Program and Administrative Costs

Year	Total Program Cost	Total Administrative Cost	Admin. Cost as % of Total Program Cost
1	\$9,760,605	217,496	2.2%
2	\$12,549,122	302,236	2.4%
3	\$15,473,007	306,770	2.0%
4	\$18,372,387	366,312	2.0%
5	\$20,384,050	371,807	1.8%

B. Problems in Establishing Base Year Costs

1. **Data Warehouse** - The Division of Health Care Financing established a data warehouse in 2001 to facilitate access to Medicaid fee-for-service data from the MMIS. Thus, to obtain historical data for this project, we were able to access the MMIS data through this avenue. As early users of a new system, we experienced some difficulties accessing data from this new source. One problem we encountered was having access to only three of the five years of historical data we originally planned to use for this proposal.
2. **HMO Data** - Medicaid contracted with four HMOs during the study period. Enrollment is mandatory for Medicaid Eligibles, including children, who live in the major urban areas. The HMO benefit package includes all Medicaid covered services with the exception of pharmacy, long-term care, and home and community-based waiver services. Since a significant number of the children to be included in the study of historical expenditures were enrolled in an HMO, we had to rely on the HMOs to provide information on other expenditures they had incurred for the children enrolled in their HMO. Although the HMOs have been required to maintain encounter data, this information is not complete with respect to the HMOs expenditures for services. Therefore, we made our request directly to the HMOs. Although they provided us with the information requested, the information was not uniform. Some HMOs lumped all their expenditures into one category, while others indicated the amount that was for inpatient services, as we requested. One HMO, American Family Care, provided the information after we had completed our study. Therefore, approximately \$100,000 in expenditures for four children in the study is not included in the calculations.
3. **Study Years** - Although our intent was to procure five years of historical data, we were able to access complete data for only the years CY1999-CY2001.
4. **Children with Life-Threatening Conditions also enrolled in Home and Community-Based Waivers** - As we compiled data for the study population, we discovered that a number of children who met the diagnostic criteria for inclusion in our study were enrolled in one of our two home and community-based waiver programs: one for technology-dependent and medically fragile children; and one for the developmentally disabled population. Since this group will not be enrolled in the Promoting HOPE program, we excluded this group from our calculations of historical cost. However, it occurred to us that the expenditures for this group could serve as a model for our cost and utilization projections for the Promoting HOPE program, since the intent of the HCBS waiver programs is similar to the intent of the Promoting HOPE program to reduce reliance on institutional care by providing support services in the community. Unfortunately, we did not collect complete expenditure data from the HMOs or death data for this group. In our projections, we estimated the amount spent by HMOs by extrapolating from the target study population.
5. **Age** - We defined the eligible population as a child 0-18 with a life-threatening condition. Moreover, if the child entered the program before age 18, and met other program criteria, the individual would remain eligible until their 22nd birthday. Therefore, in compiling the expenditure data for the study population, we included any child age 0-21.

6. **Third-Party Liability** – We were able to compile data third-party liability payments for inpatient hospital care for children on Medicaid who are also covered by other health insurance. However, the Office of Recovery Services in the Department of Human Services is responsible for third-party liability payments for other covered Medicaid services. As the Office of Recovery Services does not account for collection by client identification code, we were unable to compile this information.

C. Identifying Children with Life -Threatening Conditions – Selection Criteria

As indicated in Section VI- Eligibility, identifying children with life-threatening conditions from a Medicaid claims system was difficult at best. We researched the literature, but found no models to help us in this effort. In our attempt to estimate the size of the potential target population, it became clear that diagnosis alone was insufficient to select the target population, particularly since a variety of diseases and conditions may be considered life-threatening. Medical records would have been a better way to determine whether a child had a life-threatening condition, but this was not a practical approach. Instead we relied on various elements in Medicaid claims data, such as expenditure and utilization as well as death data to serve as a way to define potentially life-threatening conditions. (See Utah Algorithm, Appendix A-3). It should be noted we also examined the claims of children who died subsequent to receiving a Medicaid service during the period CY1995-2000. Although this group is relatively small, their expenditure data was similar to the population of children with life-threatening conditions who did not die. Since the Promoting HOPE program will serve children who are at risk of dying before age 18, but may survive for an extended period of time, we wanted to include data for both groups in our study.

Selection Process - To determine program cost in the base year, we defined our study population as follows:

1. Children, aged 0 to 21, eligible for Medicaid, not in an ICF/MR or the State Hospital; and
2. With a paid fee-for-service claim during Calendar Year 1999, 2000, 2001; and
3. With a diagnosis in any position on a paid claim that matched the diagnoses on the list of ICD-9 diagnostic codes defined as life-threatening (See Appendix A-1); and
 - a) Other meeting criteria required by the Utah Algorithm (See Appendix A-3); [In some instances, the algorithm requires an additional diagnosis, hospitalization, or procedure for children to be included in this population. Other diagnoses, such as neoplasm, do not require another element.]
 - b) **Or** hospital expenditures greater than \$185,000 in any of the study years (CY 1999 – 2000).
4. All paid Medicaid fee-for-service claims (regardless of diagnosis) were compiled for this group by year, by the individual's Medicaid ID and Social Security number and the

following 10 expenditure categories: Hospital, Outpatient hospital, Nursing facility, Home health care, Professional therapy, Physician, Pharmacy, Medical supplies, Medical Transportation, and Other which includes all other categories of service.

5. Demographic data from the eligibility file and utilization data was also compiled for each child, including the following:
 - a) Multi-Year - an indication of any other year (within CY1999-2000) in which the child had a Medicaid claim meeting the above criteria.
 - b) Diagnosis - Qualifying diagnosis. (Because these persons often had more than one diagnosis that met the criteria in the algorithm, we selected the diagnosis category based on the decision tree in Appendix A-4).
 - c) County Code - based on the last county shown in the eligibility file for that year.
 - d) Age - based on the person's last age shown on the last claim meeting the diagnosis criteria for that year.
 - e) Death Date - At the same time we compared the social security number of the persons in item 3 with Utah Vital Statistics Death data to identify any person who had died on or before September 30, 2002, subsequent to receiving a Medicaid- paid service. The age and date of death were obtained from Utah Vital Statistics data.
 - f) Category of Aid - based on the last aid category shown on the eligibility file in the year.
 - g) Total days - counted from the first date of the qualifying diagnosis to the last day in the calendar year for which the child had a qualifying claim. If the child had a qualifying diagnosis on a claim in December of the preceding year, days in the subsequent year were counted from the first date of the qualifying diagnosis in the preceding calendar year to the last day in the calendar year for which the child had a qualifying claim.
 - h) Inpatient Days - the number of days the person was in a hospital according to the claim form.
 - i) Nursing Facility Days - the number of days the person was in a nursing facility according to the claim.
 - j) HMO Data - HMOs contracting with Medicaid for the period CY1999-2000, including IHC, United, AFC, and Healthy U were given the ID numbers of the group selected above. We requested that the HMO indicate the amount they paid for any of the covered services in their contract with Medicaid for the identified person-- separating the total amount paid for inpatient care (**HMO Inpatient**) and total amount for other services (**HMO Other**). Not all the HMOs were able to separate

the data into these two categories. In such cases, payment is lumped under **HMO combined**. Please note that we did not receive complete data from AFC.

- k) Buy Out - Medicaid eligible children who have access to other health insurance who may have also incur high medical costs are referred to the buyout program. Less than 10 percent of the children in the study group were referred to the program. The amount paid for premium assistance is added to total Medicaid Expenditures.⁷
- 6. Any child who met the criteria in item 3, above, but who did not have a paid hospital or nursing facility claim during the period CY1999-2000 was excluded except the following:
 - a) A child who had died;
 - b) A child for whom a third party made a hospital payment;
 - c) A child whose paid claims for home health, physician services, pharmacy, or medical supplies were more than \$4500 in any one category in any one year;
 - d) A child who had a hospital or nursing facility claim in a prior or subsequent year.
 - 7. Diagnostic data were sorted by year into eight categories in accordance with the ICD-9 classification system: Neoplasms, Endocrine, Blood, Nervous, Circulatory, Digestive, Genito-Urinary, Congenital, and Perinatal. Cases in disease categories Endocrine, Blood, Nervous, Circulatory and Digestive, Genito-Urinary were combined under other, because of the relatively small number of cases in these categories. Thus all the summary information and projections are lumped under the following four categories: Neoplasms, Congenital, Perinatal, and Other. (See Appendix I for the raw data)
 - 8. All children who meet the above criteria are defined as the children under 21 with a life-threatening condition who may be potential Eligibles for the Promoting HOPE program and thus included in the study. As such the historical Medicaid expenditures for this group establish the baseline costs for the purpose of the projected costs under this proposal. (See Tables XI- 5A, B, and C for summary data by year for the children included in the study.) Separate summary tables are also included for children who meet the diagnostic criteria for life-threatening conditions who were enrolled in one of the home and community-based waivers (See Table XI-6A, B, and C.)
 - 9. Because there was no apparent trend in the expenditure data in CY1999-2000 and

⁷ Although there is a premium assistance program currently in place in Utah, only a small number of end-of-life-risk children with dual coverage were actually referred to the program during the waiver baseline years – less than 10%. Once the proposed identification and referral mechanisms are set in motion at the time of waiver implementation, we estimate that 70 to 90% of recipients with dual coverage recipients will be known to the Insurance Navigator. Therefore, the great majority of savings accruing to Medicaid for these recipients will be attributable to the 1115 demonstration, and not to the existing Medicaid premium assistance program.

because of the relatively small number of children in some of these categories, data was averaged for CY1999-2000 to establish base year costs.

Table XI-3: CY1999-2001 Summary of Demographic and Expenditure Data for Children with Life Threatening Conditions in the Utah Medicaid Program by Diagnostic Category

	CY1999	CY 2000	CY2001	Total	Average Number	Distribution by Diagnosis	
No. of Children							
Neoplasm	33	43	36	112	37	15.6%	
Congenital	106	67	92	265	88	37.0%	
Perinatal	53	58	53	164	55	22.9%	
Other	42	73	60	175	58	24.4%	
All	234	241	241	716	239	100.0%	
Average Age	4.9	4.8	5.0		4.9		
Days/Months					Avg. Days	Avg. Months	
Neoplasm	7,366	9,692	8,361	25,419	227.0	7.4	
Congenital	20,739	12,352	18,642	51,733	195.2	6.4	
Perinatal	9,495	11,830	7,708.00	29,033	177.0	5.8	
Other	9,908	18,966	13,780	42,654	243.7	8.0	
All	47,508	52,840	48,491	148,839	207.9	6.8	
Cost - FFS & HMO					Avg. \$/ Day	Avg. \$/ Month	Avg. \$/Year
Neoplasm	1,883,820	2,469,595	2,338,621	6,692,036	263.27	8,030	59,750
Congenital	4,103,352	1,993,468	3,231,466	9,328,287	180.32	5,500	35,201
Perinatal	7,345,291	7,542,551	5,913,152	20,800,994	716.46	21,852	126,835
Other	2,501,035	3,486,603	3,592,940	9,580,578	224.61	6,851	54,746
All	15,833,499	15,492,217	15,076,179	46,401,895	311.76	9,509	64,807
Institutional Days					Avg. Days/Child		
Neoplasm	348	590	576	1,514	14		
Congenital	1,580	879	1,415	3,874	15		
Perinatal	3,510	1,750	2,889	8,149	50		
Other	1,503	1,280	2,074	4,857	28		
All	6,941	4,499	6,954	18,394	26		
Institutional Cost					Avg. Cost/Day	Av Annual Cost	Percent of Total Cost
Neoplasm	487,829	1,314,803	784,261	2,586,892	1,709	23,097	38.7%
Congenital	2,962,866	818,865	2,308,395	6,090,126	1,572	22,982	65.3%
Perinatal	6,684,485	6,686,270	5,347,657	18,718,413	2,297	114,137	90.0%
Other	1,172,139	1,953,100	2,423,254	5,548,494	1,142	31,706	57.9%
All	11,307,320	10,773,038	10,863,567	32,943,925	1,791	46,011	71.0%

Table XI-4: CY1999-2000 Summary of Demographic Data and Expenditures for Children with Life-Threatening Conditions in a Utah Home and Community-Based Waiver

					3-Year Average		
	CY1999	CY 2000	CY2001	Total	Average Number	Percentage Distribution	
No. of Children							
Tech Waiver	19	27	35	81	27	57.4%	
DD Waiver	19	19	23	61	20	43.3%	
All Waiver	38	46	58	142	47	100.7%	
Days/Months					Avg. Days	Avg. Months	
Tech Waiver	5,641	7,445	9,320	22,406	276.6	9.1	
DD Waiver	6,670	6,832	8,257	21,759	356.7	11.7	
All Waiver	12,311	14,277	17,577	44,165	311.0	10.2	
Cost FFS					Avg. \$/ Day	Avg. \$/Month	Avg. \$/Year
Tech Waiver	923,015	649,042	988,006	2,560,063	114.26	3,485	31,606
DD Waiver	227,515	372,427	250,540	850,482	39.09	1,192	13,942
All Waiver	1,150,530	1,021,470	1,238,545	3,410,545	77.22	2,355	24,018
FFS Cost + Estimated HMO Expenditures					Avg. \$/ Day	Avg. \$/Month	Avg. \$/ Year
Tech Waiver	923,015	649,042	988,006				
HMO % addition	0.114	0.159	0.140				
HMO estimate	105,224	103,198	138,321				
Total	1,028,238	752,240	1,126,326	2,906,805	129.73	3,957	35,886
DD Waiver	227,515	372,427	250,540				
HMO % addition	0.114	0.159	0.140				
HMO estimate	25,937	59,216	35,076				
Total	253,452	431,643	285,616	970,711	44.61	1,361	15,913
All Waiver	1,281,690	1,183,883	1,411,942	3,877,515	87.80	2,678	27,306
Hospital Days					Avg./Child		
Tech Waiver	366	633	119	1118	13.8		
DD Waiver	41	59	18	118	1.9		
All Waiver	407	692	137	1236	8.7		
Institutional Cost					Avg. Annual Cost	% of Total Cost	
Tech Waiver	434,410	212,623	329,185	976,218	12,052	38.1%	
DD Waiver	78,643	196,373	52,999	328,015	5,377	38.6%	
All Waiver	513,053	408,996	382,184	1,304,233	9,185	38.2%	
Services with Limited Insurance Coverage					Medicaid Costs		
					for Insured Group*	Non-Insured Group**	
Home Health	376,072	302,906	483,055	1,162,034	387,345	774,689	
Professional Therapy	2,450	5,195	8,814	16,459	5,486	10,973	
Medical Supplies	68,728	64,598	57,494	190,820	63,607	127,213	
Medical Transportation	6,248	2,140	2,797	11,185	3,728	7,457	
Total	453,498	374,839	552,161	1,380,498	460,166	920,332	
% of total days				100	40	60	
share of total days				44,165	17,666	26,499	
average daily cost				31.26	26.05	34.73	
average monthly cost				953	794	1,059	

* Medicaid cost for insured HCBS group is estimated to be about one third of the total Medicaid cost. ** Medicaid cost for

non-insured HCBS group is estimated to be 2/3s of the total Medicaid cost.

Table XI-5A: CY 1999 Summary of Utah Medicaid Expenditures and Demographic Data for Children with Life-threatening Conditions - Potential Enrollees in the Promoting HOPE Program

	Neoplasms	Congenital	Perinatal	Other	Total All Dx Groups	Average All Groups	Percent of Grand Total	Percent of Fee-for-Service
Demographics								
Number of Children	33	106	53	42	234	234		
Percent Distribution	14.1%	45.3%	22.6%	17.9%	100.0%			
Average Age								
Deaths 1/99-9/02	9	7	1	3	20			
Total Days Eligible	7,366	20,739	9,495	9,908	47,508			
Avg. Number of Days Eligible	223.2	195.7	179.2	235.9	203.0			
Avg. No. of Months in Care	7.3	6.4	5.9	7.7	6.7			
Avg. Cost/Child/Day	255.75	197.86	773.60	252.43	333.28			
Avg. Cost/Child/Month	7,800	6,035	23,595	7,699	10,165			
Aver. Cost/Child/Annual	57,085	38,711	138,590	59,548	67,665			
Expenditures								
Hospital	487,829	2,957,749	6,684,485	493,961	10,624,023	45,402	67.1%	75.8%
Outpatient Hospital	113,303	123,437	11,945	60,484	309,169	1,321	2.0%	2.2%
Nursing Facility	0	5,118	0	678,179	683,297	2,920	4.3%	4.9%
Home Health	9,034	36,193	94,007	17,833	157,067	671	1.0%	1.1%
Professional Therapy	1,654	2,837	299	4,464	9,254	40	0.1%	0.1%
Physician	85,945	283,667	396,795	61,439	827,846	3,538	5.2%	5.9%
Pharmacy	66,154	70,298	6,476	923,859	1,066,787	4,559	6.7%	7.6%
Medical Supplies	18,589	56,328	20,752	47,753	143,423	613	0.9%	1.0%
Medical Transportation	3,891	15,786	15,370	5,247	40,295	172	0.3%	0.3%
Other	7,965	61,596	34,687	45,196	149,444	639	0.9%	1.1%
Total Fee-For-Service	794,364	3,613,010	7,264,817	2,338,415	14,010,606	59,874	88.5%	100.0%
HMO Total	1,087,460	480,795	75,370	162,620	1,806,245	7,719	11.4%	
Buy Out	1,996	9,548	5,104	0	16,648	71	0.1%	
Grand Total	1,883,820	4,103,352	7,345,291	2,501,035	15,833,499	67,665	100.0%	
Other Payments						0		
No. in HMO	10	39	16	19	84		35.9%	
Premiums Paid to HMOs	27,776	71,864	30,515	39,047	169,201	2,014	1.1%	1.2%
Hospital TPL Collections	25,458	332,934	120,600	49,454	528,446	2,258	3.3%	3.8%
Utilization								
FFS Hospital Days	348	1,524	3,510	298	5,680	24		
FFS Nursing Facility Days	0	56	0	1,205	1,261	5		
Total FFS Institutional Days	348	1,580	3,510	1,503	6,941	30		
No. In Multiple Years	10	14	5	9	38			

Table XI-5B: CY 2000 Summary of Utah Medicaid Expenditure and Demographic Data for Children with Life-threatening Conditions Potential Enrollees in the Promoting HOPE Program

	Neoplasms	Congenital	Perinatal	Other	Total All Dx Groups	Average All Groups	Percent of Grand Total	Percent of Fee-for-Service
Demographics								
Number of Children	43	67	58	73	241			
Percent Distribution	17.8%	27.8%	24.1%	30.3%	100.0%			
Average Age								
Deaths 1/99-9/02	7	2	1	5	15			
Total Days Eligible	9,692	12,352	11,830	18,966	52,840	219.3		
Avg. Number of Days Eligible	225.4	184.4	204.0	259.8	219.3			
Avg. No. of Months in Care	7.4	6.0	6.7	8.5	7.2			
Avg. Cost/Child/Day	255	161	638	184	293			
Avg. Cost/Child/Month	7,772	4,922	19,446	5,607	8,942			
Avg. Cost/Child/Annual	57,432	29,753	130,044	47,762	64,283			
Expenditures								
Hospital	1,314,803	799,596	6,686,270	1,362,186	10,162,855	42,170	65.6%	78.1%
Outpatient Hospital	123,018	37,536	24,765	121,106	306,425	1,271	2.0%	2.4%
Nursing Facility	0	19,269	0	590,914	610,183	2,532	3.9%	4.7%
Home Health	9,965	100,931	12,884	12,385	136,164	565	0.9%	1.0%
Professional Therapy	260	385	476	5,631	6,752	28	0.0%	0.1%
Physician	110,594	122,144	478,534	181,521	892,793	3,705	5.8%	6.9%
Pharmacy	95,833	46,687	15,205	252,595	410,320	1,703	2.6%	3.2%
Medical Supplies	35,942	72,345	29,402	81,732	219,421	910	1.4%	1.7%
Medical Transportation	10,559	6,873	16,179	12,574	46,185	192	0.3%	0.4%
Other	11,234	46,587	81,161	90,202	229,185	951	1.5%	1.8%
Total Fee-For-Service	1,712,207	1,252,353	7,344,878	2,710,845	13,020,283	54,026	84.0%	100.0%
HMO Total	754,440	741,115	194,210	775,758	2,465,523	10,230	15.9%	
Buy Out	2,948	0	3,463	0	6,411	27	0.0%	
Grand Total	2,469,595	1,993,468	7,542,551	3,486,603	15,492,217	64,283	100.0%	
Other Payments								
No. in HMO	18	21	21	28	88		36.5%	
Premiums Paid to HMOs	9,605	13,541	25,681	15,972	64,799	736		0.005
Hospital TPL Collections	14,112	53,750	56,294	582,293	706,449	2,931		5.4%
Utilization								
FFS Hospital Days	559	879	1750	931	4,119	17		
FFS Nursing Facility Days	31	0	0	349	380	2		
Total FFS Institutional Days	590	879	1750	1280	4499	19		
No. In Multiple Years	19	16	10	22	67			

Table XI-5C: CY 2001 Summary of Utah Medicaid Expenditures and Demographic Data for Children with Life-threatening Conditions - Potential Enrollees in the Promoting HOPE Program

	Neoplasms	Congenital	Perinatal	Other	Total All Dx Groups	Average All Groups	Percent of Grand Total	Percent of Fee-for-Service
Demographics								
Number of Children	36	92	53	60	241	241		
Percent Distribution								
Average Age								
Deaths 1/99-9/02	2	2	3	1	8			
Total Days Eligible	8,361	18,642	7,708.00	13,780	48,491			
Avg. Number of Days Eligible	232.3	202.6	145.4	229.7	201.2			
Avg. No. of Months in Care	7.6	6.6	4.8	7.5	6.6			
Avg. Cost/Child/Day	279.71	173.34	767.14	260.74	310.91			
Avg. Cost/Child/Month	8,531	5,287	23,398	7,952	9,483			
Avg. Cost/Child/Annual	64,962	35,125	111,569	59,882	62,557			
Expenditures								
Hospital	634,731	2,247,260	5,347,657	1,807,525	10,037,173	41,648	66.6%	77.5%
Outpatient Hospital	53,545	80,745	6,602	101,796	242,688	1,007	1.6%	1.9%
Nursing Facility	149,530	61,135	0	615,729	826,394	3,429	5.5%	6.4%
Home Health	2,565	79,642	4,121	17,927	104,255	433	0.7%	0.8%
Professional Therapy	403	565	895	6,198	8,062	33	0.1%	0.1%
Physician	72,534	254,036	401,779	196,353	924,703	3,837	6.1%	7.1%
Pharmacy	141,460	63,786	8,862	199,503	413,611	1,716	2.7%	3.2%
Medical Supplies	21,967	63,321	21,120	67,392	173,800	721	1.2%	1.3%
Medical Transportation	2,593	19,365	15,770	12,256	49,984	207	0.3%	0.4%
Other	10,290	64,728	30,445	65,086	170,549	708	1.1%	1.3%
Total Fee-For-Service	1,089,619	2,934,582	5,837,253	3,089,766	12,951,219	53,739	85.9%	100.0%
HMO Total	1,245,784	296,884	70,261	496,997	2,109,926	8,755	14.0%	
Buy Out	3,219	0	5,638	6,178	15,034	62	0.1%	
Grand Total	2,338,621	3,231,466	5,913,152	3,592,940	15,076,179	62,557	100.0%	
Other Payments								
No. in HMO	20	38	19	20	97		40.2%	
Premiums Paid to HMOs	18,797	78,233	20,831	21,926	139,787	1,441		
Hospital TPL Collections	55,468	165,141	280,954	265,476	767,039			5.9%
Utilization								
FFS Hospital Days	192	1,271	2,889	896	5,248	22		
FFS Nursing Facility Days	384	144	0	1,178	1,706	7		
Total FFS Institutional Days	576	1,415	2,889	2,074	6,954	29		
No. In Multiple Years	7	6	0	7	20			

Table XI-6A: CY 1999 Summary of Utah Medicaid Expenditures and Demographic Data for Children with Life-threatening Conditions in HCBS Waivers by Type of Waiver

	Technology Dependent	Develop- mentally Disabled	Total Waiver Group	Percent of Fee-for- Service	Average Waiver Group
Demographics					
Number of Children	19	19	38		38
Percent Distribution	50.0%	50.0%	100.0%		
Total Days Eligible	5,641	6,670	12,311		
Avg. Number of Days Eligible	297	351	324		
Avg. No. of Months in Care	10	12	11		
Avg. Cost/Child/Day	164	34	93		
Avg. Cost/Child/Month	4,991	1,040	2,850		
Avg. Cost/Child/Annual	48,580	11,974	30,277		
Expenditures					
Hospital	434,410	78,643	513,053	44.6%	13,501
Outpatient Hospital	4,807	11,749	16,557	1.4%	436
Nursing Facility	0	0	0	0.0%	0
Home Health	356,624	19,448	376,072	32.7%	9,897
Professional Therapy	97	2,353	2,450	0.2%	64
Physician	35,521	13,570	49,091	4.3%	1,292
Pharmacy	28,980	25,495	54,475	4.7%	1,434
Medical Supplies	39,270	29,458	68,728	6.0%	1,809
Medical Transportation	4,796	1,452	6,248	0.5%	164
Other	18,508	45,348	63,856	5.6%	1,680
Total Fee-For-Service	923,015	227,515	1,150,530	100.0%	30,277
Other Payments					
Premiums Paid to HMOs	0	0	0		
Hospital TPL Collections	355,789	0	355,789	30.9%	
Utilization					
FFS Hospital Days	366	41	407		11
FFS Nursing Facility Days	0	0	0		0

Table XI-6B: CY 2000 Summary of Utah Medicaid Expenditures and Demographic Data for Children with Life-threatening Conditions in HCBS Waivers by Type of Waiver

	Technology Dependent	Develop- mentally Disabled	Total Waiver Group	Percent of Fee-for- Service	Average Waiver Group
Demographics					
Number of Children	27	19	46		46
Percent Distribution	58.7%	41.3%	100.0%		
Total Days Eligible	7,445	6,832	14,277		
Avg. Number of Days Eligible	275.7	359.6	310.4		
Avg. No. of Months in Care	9.0	11.8	10.2		
Avg. Cost/Child/Day	87	55	72		
Avg. Cost/Child/Month	2,659	1,663	2,182		
Avg. Cost/Child/Annual	24,039	19,601	22,206		
Expenditures					
Hospital	199,619	196,373	395,992	38.8%	8,609
Outpatient Hospital	6,132	8,559	14,691	1.4%	319
Nursing Facility	13,004	0	13,004	1.3%	283
Home Health	270,015	32,891	302,906	29.7%	6,585
Professional Therapy	981	4,214	5,195	0.5%	113
Physician	28,276	18,305	46,581	4.6%	1,013
Pharmacy	26,835	24,207	51,043	5.0%	1,110
Medical Supplies	20,400	44,198	64,598	6.3%	1,404
Medical Transportation	750	1,390	2,140	0.2%	47
Other	83,030	42,290	125,320	12.3%	2,724
Total Fee-For-Service	649,042	372,427	1,021,470	100.0%	22,206
Other Payments					
Premiums Paid to HMOs	16,911	3,617	20,528	2.0%	
Hospital TPL Collections	45,326	3,242	48,568	4.8%	
Utilization					
FFS Hospital Days	633	59	692		15
FFS Nursing Facility Days	0	726	726		16

Table XI-6C: CY 2001 Summary of Utah Medicaid Expenditures and Demographic Data for Children with Life-threatening Conditions in HCBS Waivers by Type of Waiver

	Technology Dependent	Develop- mentally Disabled	Total Waiver Group	Percent of Fee-for- Service	Average Waiver Group
Number of Children	35	23	58		58
Percent Distribution					
Average Age					
Deaths 1/99-9/02					
Total Days Eligible	9,320	8,257	17,577		
Avg. Number of Days Eligible	266.3	359.0	303.1		
Avg. No. of Months in Care	13.3	7.7	9.9		
Avg. Cost/Child/Day	106.01	30.34	70.46		
Avg. Cost/Child/Month	3,233	925	2,149		
Avg. Cost/Child/Annual	28,229	10,893	21,354		
Expenditures					
Hospital	206,952	52,999	259,952	21.0%	4,482
Outpatient Hospital	4,931	14,596	19,527	1.6%	337
Nursing Facility	122,232	0	122,232	9.9%	2,107
Home Health	439,262	43,794	483,055	39.0%	8,329
Professional Therapy	5,549	3,265	8,814	0.7%	152
Physician	40,076	12,886	52,962	4.3%	913
Pharmacy	53,061	38,589	91,650	7.4%	1,580
Medical Supplies	24,372	33,122	57,494	4.6%	991
Medical Transportation	2,552	245	2,797	0.2%	48
Other	89,017	51,045	140,062	11.3%	2,415
Total Fee-For-Service	988,006	250,540	1,238,545	100.0%	21,354
Other Payments					
Premiums Paid to HMOs	61,884	11,775	73,660		
Hospital TPL Collections	11,814	4,177	15,991	1.3%	
Utilization					
FFS Hospital Days	119	18	137		2
FFS Nursing Facility Days	196	0	196		3

D. Summary and Explanation of Historical Data (Base Years: CY1999-CY2001)

1. **Age Distribution** - The majority of children in the study group are under age one; the average age of all children in the study group ranges from 4.8 years in CY 2000 to 5.0 years in CY2001. (See table XI-7 and Figure XI-1)

Table XI-7: CY 1999 - 2000 Average Age of Study Population

CY	Age in Years						Total Cases	Average Age
	Under 1	1 - 2	3 - 5	6 - 12	13 - 18	19 - 21		
1999	121	36	14	20	23	20	234	4.9
2000	114	40	25	23	22	17	241	4.8
2001	133	33	13	14	27	21	241	5.0

2. **Urban-Rural Distribution** - Slightly more than half the children in the study population were from rural areas of the state, where HMO enrollment is not mandatory. The number of children in rural areas ranged from 52 percent in CY 2001, to about 56 percent in CY 2000. (See table XI-8 and Figure XI-2.) For all Medicaid eligibles, approximately 67 percent are from urban areas, while 33 percent are from rural areas. Since HMO enrollment is mandatory for most, though not all, Medicaid eligibility groups in urban areas it is interesting to note that in CY 2001 only 36 to 40 percent of the children in the study group were enrolled in an HMO. This may occur because children who are in long-term care or have hospital stays of more than 30 days are not automatically enrolled in an HMO. Furthermore, if the child is eligible for Medicaid only while in the hospital, the child may not be enrolled in an HMO.

Figure XI – 1: CY 1999 - 2000 Age Distribution of Study Population

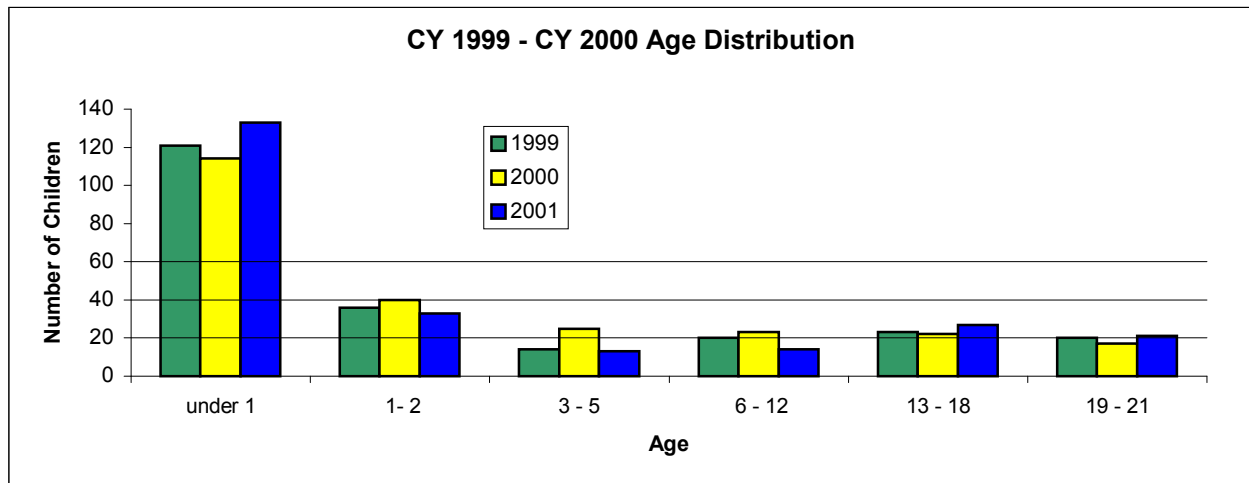
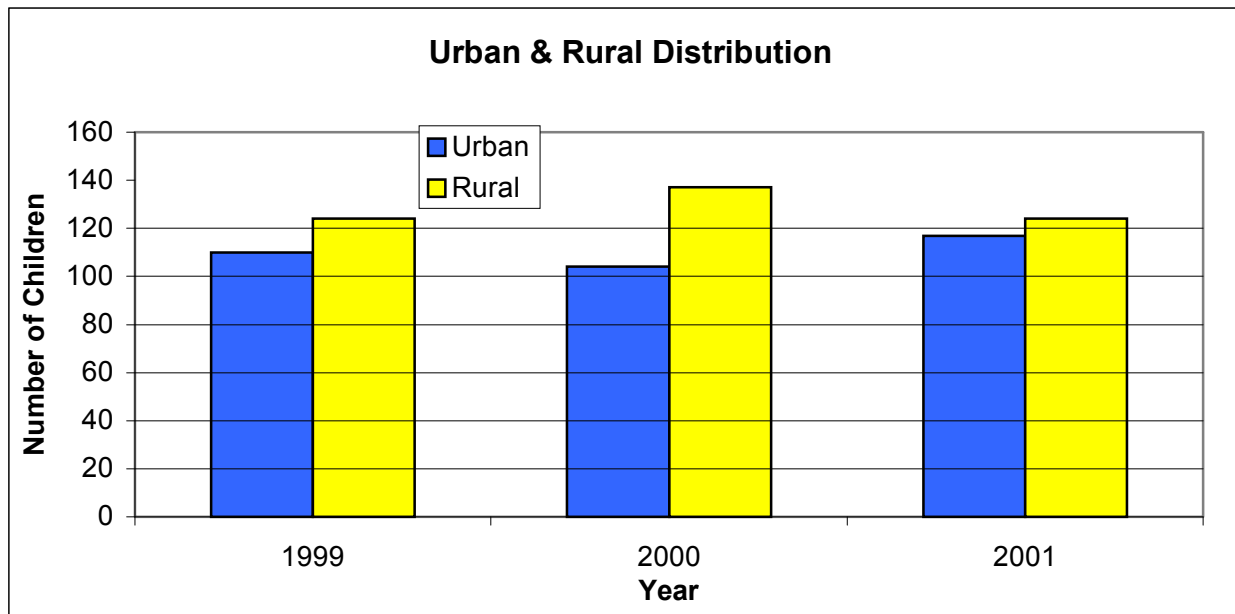


Figure XI – 2: CY 1999 - 2001 Urban and Rural Distribution of Children with Life-Threatening Conditions



3. **Other Demographic Data** - The number of children in the study group was 234 in CY 1999, 241 in both CY 2000 and CY 2001. The information in the summary tables (See Table XI- 5A-C) is summarized by four major diagnostic categories. The “Other” group includes Endocrine, Blood, Nervous, Circulatory and Digestive, and Genito-Urinary. Except for CY 2000, the Congenital group has the largest number of children, followed by Perinatal and Neoplasms. For the most part, children in the Perinatal group had the shortest length of stay, from 4.8 months in CY2001 to 5.9 months in CY 1999; while the longest length of stay varied from 8.5 months for the “Other” group in CY 2000 to 7.7 in CY 1999.
4. **Cost of Care**- The average monthly cost of care also varied from a low of \$4,922 per month for the Congenital group in CY 2000 to \$6,035 per month in CY 1999; while the highest cost per month was consistently for the Perinatal group from a low of \$19,446 in CY 2000 to a high of \$23,595 in CY 1999. The average annual cost for all diagnostic groups varied from a high of \$67,665 in CY 1999 to a low of \$62, 557 in CY 2001.

In CY1999, about 76 percent of the average annual fee-for-service expenditures were for inpatient hospital care; and that figure increased to about 78 percent in CY2000 and CY2001. For the three study years, HMOs paid only 11 to 16 percent of the total cost.

In analyzing the summary data for CY 1999 - 2001, no definitive trends emerge.

Table XI-8: CY 1999 - 2001 Urban and Rural Distribution of Children with Life-Threatening Conditions

		CY1999		CY2000		CY2001	
Number			234		241		241
Urban		Cases	%	Cases	%	Cases	%
6	Davis	7	3.0%	5	2.1%	19	7.9%
18	Salt Lake	70	29.9%	65	27.0%	54	22.4%
25	Utah	21	9.0%	18	7.5%	30	12.4%
29	Weber	12	5.1%	16	6.6%	14	5.8%
Subtotal		110	47.0%	104	43.2%	117	48.5%
Rural			0.0%				
1	Beaver	1	0.4%	4	1.2%	3	1.2%
2	Box Elder		1.7%	6	2.5%	11	4.6%
3	Cache	25	10.7%	32	13.3%	12	5.0%
4	Carbon	12	5.1%	14	5.8%	16	6.6%
5	Daggett	0	0.0%		0.0%		0.0%
7	Duchesne	2	0.9%	7	2.9%	4	1.7%
8	Emery	7	3.0%	4	1.7%	6	2.5%
9	Garfield	0	0.0%	1	0.4%		0.0%
10	Grand	1	0.4%	2	0.8%	1	0.4%
11	Iron	12	5.1%	7	2.9%	9	3.7%
12	Juab	3	1.3%	7	2.9%	4	1.7%
13	Kane	1	0.4%	3	1.2%	2	0.8%
14	Millard	1	0.4%	3	1.2%	4	1.7%
15	Morgan	0	0.0%		0.0%		0.0%
16	Piute	0	0.0%		0.0%	1	0.4%
19	San Juan	6	2.6%	4	1.7%	4	1.7%
20	San Pete	5	2.1%		0.0%	10	4.1%
21	Sevier	5	2.1%	6	2.5%	6	2.5%
22	Summit	3	1.3%	5	2.1%	3	1.2%
23	Tooele	6	2.6%	9	3.7%	7	2.9%
24	Uintah	10	4.3%	10	4.1%	8	3.3%
26	Wasatch	3	1.3%		0.0%	2	0.8%
27	Washington	17	7.3%	13	5.4%	11	4.6%
28	Wayne	0	0.0%		0.0%		0.0%
Subtotal		124	53.0%	136	56.4%	124	51.5%
Grand Total		234	100.0%	241	100.0%	241	100.0%

E. Projections

All budget projections are based on an average of the three-year historical costs for the study group. We believe averaging is justified because of the relatively small numbers of cases in each of the diagnostic categories and because there were no clear trends in either enrollment or expenditures over the three year period. Each of the variables used in the projections to estimate the cost of the program during the five-year period of the proposed program are described below including the rationale or the assumption for the projections.

1. **Projecting Annual Enrollment:** Since the program will eventually be open to all children with life-threatening conditions who reside in Utah, regardless of income, projections are based on the estimated number of children in Utah with a life-threatening condition. In Section VI - Eligibility, we estimated that approximately 1000 children might suffer from a life-threatening condition.

These 1,000 potential Eligibles are distributed by the income distribution of Utah households. The uninsured group and those children we identified in the home and community based waivers are subtracted to show the remaining number of potential Eligibles for the Promoting HOPE program (Table XI-9). The number of potential Eligibles is greater than the number likely to enroll. We estimate that only 67% of the Medicaid group will enroll because a significant number of children with life-threatening conditions are infants who die within a few days of birth and may die in the hospital. Furthermore, not all families may need or wish to avail themselves of the services in Package B. We estimate that only 36 percent of the families in the expanded group income range will enroll for some of the same reasons as the Medicaid group, but also because the enrollment fee for this group may be a deterrent. The steep enrollment fee for the highest income groups makes it less likely that any in this group will enroll.

Table XI-9: Estimating the Number Likely to Enroll in the Promoting HOPE Program Based on Medicaid Historical Data and Utah Household Income Distribution

	Distribution by Income	Potential Enrollees (1000)	Uninsured (4%)	HCBS Waiver (16%)	Remaining Potential Enrollees	Number Likely to Enroll
Medicaid & low income	0.291	291	12	45	235	159
CHIP	0.142	142	N/A	N/A	N/A	
Expanded Group	0.482	482	19	17	446	160
High Income	0.085	85	3	N/A	90	0
Total	1	1000	40	50	770	319

Of the group that is likely to enroll, the numbers in the Medicaid group and the Expanded Group are delineated in Table XI-10, below.

Table XI–10: Number of Likely Enrollees in the Promoting HOPE Program by Year

Number of Likely Enrollees in the Promoting HOPE Program by Year*					
	FY2004	FY2005	FY2006	FY2007	FY2008
Number likely to Enroll	Year One	Year Two	Year Three	Year Four	Year Five
Medicaid	120	126	145	156	159
Medicaid Growth .04		5	6	6	6
Total Medicaid	120	131	151	162	165
Expanded Group - Hospice		50	50	72	80
Expanded Group - Non- Hospice		50	50	73	80
Expanded Growth			1	2	2
Total Expanded		100	101	147	162
Grand Total	120	231	252	309	327

*Any new program takes time to become established. Therefore, it is estimated that the population likely to enroll will not reach a maximum until year five.

The Medicaid group includes all children eligible for Medicaid under the eligibility criteria in the State Plan. The Expanded Group is divided into Expanded - Hospice: those eligible for Medicaid under the Medicaid State Plan Option for children who meet institutional admission criteria and elect hospice care (see page 120-121) regarding waiver requested for this option); and Expanded - Non Hospice: those children who do not qualify for Medicaid under the State Plan. In addition we have added children to account for the expected average 4 % annual growth rate over the five-year period.

Table XI–11: Utah Births 1995 – 1999

Year	Total Utah Births	Percent Change from Previous Year
1995	39,554	
1996	42,056	0.063
1997	43,009	0.023
1998	45,128	0.049
1999	46,243	0.025
Average growth rate		0.040

Since the program will be open only to regular State Plan Medicaid eligibles in the first year of the program, enrollment will be phased in to meet the peak number by year five. Any new program takes time to become known and established, even with our planned outreach efforts.

- 2. Projecting Average Monthly Enrollment** - The projected average monthly enrollment is calculated (Table XI-13) based on the length of stay for the children in the study group (Table XI-12).

Table XI-12: CY 1999 - 2001 Historical Distribution by LOS and Disease Classification

Condition	Distribution of Children by LOS				Totals
	< 3 Mos.	3 to <6 Mos.	6 to <9 Mos.	9 to 12 Mos.	
Neoplasms	7	5	8	17	37
Congenital	25	16	17	31	88
Perinatal	14	14	14	12	55
Other	10	8	11	30	58
All	57	42	50	90	239
Estimated Average Historical LOS and Average Historical Monthly Caseload					
Midpoint of Stay	1.5	4.5	7.5	10.5	
Estimated Case-Months	85	187.5	377.5	945	1,595
Average Cases/Month					133
Distribution by LOS	23.7%	17.5%	21.1%	37.7%	100.0%

In Year One, the average monthly enrollment is estimated at 67 cases per month; 129 in Year 2, 140 in Year 3, 172 in Year 4, and 182 in Year 5. The average caseload for a full-time equivalent (FTE) Care Coordinator will be about 60 cases, for the Outreach Coordinator between 120-150 cases, and for an Insurance Navigator 150 to 180 cases.

Table XI-13: Projected Monthly Average Caseload

		< 3 Mos.	3 to <6 Mos.	6 to <9 Mos.	9 to 12 Mos.	Total
Year 1	No. Children	120	28	21	25	45
	Total Months		42.7	94.3	189.8	475.1
	Av. Cases Month					67
Year 2	No. Children	231	55	40	49	87
	Total Months		82.3	181.5	365.4	914.6
	Av. Cases Month					129
Year 3	No. Children	252	60	44	53	95
	Total Months		89.7	198.0	398.6	997.8
	Av. Cases Month					140
Year 4	No. Children	309	73	54	65	117
	Total Months		110.0	242.8	488.7	1223.5
	Av. Cases Month					172
Year 5	No. Children	327	78	57	69	123
	Total Months		116.5	256.9	517.2	1294.8
	Av. Cases Month					182

- Projecting Case Mix:** Although we averaged all three years to establish an average case mix, we believe that the number of children who will enroll in the Perinatal group will be lower than the historical average would indicate, in part because this group is more likely to die in the hospital. To better estimate the case mix, we included a factor related to the likelihood of death in the diagnostic group. We averaged the diagnostic percentages and the percentage distribution of deaths to calculate a case mix that we believe will be more representative of the group that will enroll. We believe that this approach factors the requirement for admission that the child is likely to die before reaching adulthood. As

we have no way to predict how the case mix might change during the five-year period, we have left it constant.

Table XI–14: Projecting Case Mix with Historical Distribution and Number of Deaths

Projected Enrollment by Dx Group	Neoplasm	Congenital	Perinatal	Other	All
Historical Percent Distribution	15.6%	37.0%	22.9%	24.4%	100%
Deaths	18	11	5	9	43
Percent of All Deaths	41.9%	25.6%	11.6%	20.9%	100.0%
Avg. % of Historical Distribution & Deaths	28.8%	31.3%	17.3%	22.7%	100.0%

4. **Projecting Average Eligible Months:** The historical average monthly length of stay on Medicaid for all diagnostic groups is 6.8 months for the study group (Table XI-15) and 10.2 months for the children in the home and community-based waiver programs (Table XI-16). Since a program goal is to allow families to access support services earlier in the child's illness, we have increased the projected length of stay for each diagnostic group by 20 percent to bring it closer to the average for the children in the HCBS waiver group.

Table XI–15: Historical & Projected Average Length of Stay for Potential Target Group

	Neoplasm	Congenital	Perinatal	Other	All
CY1999-2001 Historical Average					
Average Number of Children	37	88	55	58	239
Monthly LOS	7.4	6.4	5.8	8.0	6.8
Projected LOS increase by 20%	8.9	7.7	7.0	9.6	8.2
Projected LOS for Hospice State Plan Group - Without 1115 Demonstration (estimated average length of stay)					4.0
Projected LOS for Hospice State Plan Group - With 1115 Demonstration (increase by 20%)					4.8

Table XI–16: Historical Average Length of Stay for Comparison HCBS Waiver Group

	Tech	DD	All
CY1999-2001 Historical Average			
Average Number of Children	27	20	40
LOS (Months)	9.1	11.7	10.2

5. Projecting Monthly Cost

- a) **Projecting Average Monthly Cost for Medicaid State Plan Eligibles -** The historical average monthly Medicaid expenditures (including HMO expenditures) varies by diagnostic category over the three historical study years. The only constant is for the Perinatal group. Their cost is three to five times that of the other diagnostic groups. Since a program goal is to reduce the need for expensive inpatient care (hospital and nursing facility) by offering additional support services to families who wish to care for their child at home, we believe we should see a reduction in the

monthly cost of care for all groups who participate in the program. As is evident in Table XI-18, the historical average institutional costs, as a percentage of the total cost for the children in the study group is 71 percent. The high ratio of institutional to community-based cost is due in part due to current Medicaid eligibility rules that count the child's income only when the child is institutionalized, but deems parental income when the child returns home. Therefore, hospital stay for this group may be artificially long. If eligibility for care was not predicated on place of care and financial and other supportive were available for home care, the institutional length of stay could be shortened. There is considerable anecdotal evidence from focus groups, news stories, discussions with hospital staff, and in the current literature that children might spend fewer days in the hospital, if there were other options for care. The best evidence to support a reduction in institutional days is to look at the historical data for children with similar life-threatening conditions in Utah's two home and community-based waiver programs. For this group the ratio of institutional to community-based costs is on average 38 percent (see Table XI-17).

We project a more conservative ratio of about institutional cost to community-based costs for the Promoting HOPE program. To approach this ratio we estimate a 40 percent reduction in the number of hospital and nursing facility days which brings the estimated institutional cost as a percentage of total cost of State Plan services to about 60 percent. This is a conservative estimate, as the percentage is still considerably higher than the 38 percent for children in the HCBS waivers (see table XI-17). The average cost of an institutional day was calculated by dividing total number of hospital days into the total Medicaid FFS expenditures for hospital and nursing facility care for the study population.

The adjusted projected average annual cost of State Plan services for each of the diagnostic groups can be found in Table XI-18. The estimated cost of new services will increase the monthly average for the Medicaid group (See Table XI-20 for the projected cost of new services). It should be noted that this monthly average cost is still considerably higher than for the HCBS Waiver group (compare to Table XI-17). The average monthly cost for children in the HCBS Waiver includes State Plan as well as waiver services.

Table XI-17: The Historical Average Cost of All Services for HCBS Group

CY1999-2001 Historical Average	HCBS Waiver		
	Tech	DD	Total
Average Monthly Cost	\$ 3,957	\$ 1,361	\$ 2,678
CY1999-2001 Avg. Annual Cost	\$ 35,886	\$ 15,913	\$ 27,036
Institutional Cost as % of Total Cost	38.1%	38.6%	38.2%
Avg. Number of Institutional Days	14	2	9

Table XI-18: Projecting Monthly Average Cost of State Plan Services for Medicaid Group

	Neoplasm	Congenital	Perinatal	Other	All
CY1999-2001 Historical Average					
Average Number of Children	37	88	55	58	239
Monthly LOS	7.4	6.4	5.8	8.0	6.8
Average Monthly Cost	8,030	5,500	21,852	6,851	9,509
CY1999-2001 Avg. Annual Cost	59,750	35,201	126,835	54,746	64,807
Institutional Cost as Percentage of Total Cost	38.7%	65.3%	90.0%	57.9%	71.0%
Avg. Number of Institutional Days	13.5	14.6	49.7	27.8	25.7
Institutional Cost	23,097	22,982	114,137	31,706	46,011
Projected Monthly - Medicaid Group with 1115 Demonstration					
Reduce Institutional Days by 40%	5.4	5.8	19.9	11.1	10.3
Avg. Institutional Cost/Day	1,709	1,572	2,297	1,142	1,791
Annual Cost Reduction	9,239	9,193	45,655	12,682	18,404
Adjusted Annual Cost	50,511	26,008	81,181	42,064	46,403
Adjusted Institutional Cost	13,858	13,789	68,482	19,024	27,607
Estimated Institutional Cost as percent of total cost	27.4%	53.0%	84.4%	45.2%	59.5%
Projected Average Monthly Cost	6,788	4,063	13,986	5,264	6,808

- b) **Projecting Monthly Cost of State Plan Services for Expanded Group - Hospice -**
We estimate the cost of state plan services for this group separately with and without the Section 1115 demonstration because the utilization of services will differ under the two scenarios.

Table XI-19A : Projected Average Monthly Cost for State Plan Services for Expanded Group - State Plan Hospice

Without 1115 Demonstration					
	Average daily hospice rate	Add 5% for State Plan -MD Service	Days per month	Total Estimated Hospice State Plan	All Without 1115 Waivers
hospice daily rate * 30 days	115	6	30.5	3,691	3,691
Adjusted Projected Cost (hospice rate)					3,691

Without the 1115 demonstration, the group would likely have no other insurance coverage, would qualify for Medicaid because they select to receive hospice care, and consequently would not be eligible for State Plan services that are curative in nature. Thus the estimated monthly cost is estimated using an average of the current daily hospice rate for Utah urban areas (\$118) and the Utah rural rate of (\$111) for an average of \$115 per day. An additional 5 percent is added for physician services that are allowed in addition to the hospice rate. We have used a conservative figure and have not included an allowance for any of the higher hospice payment rates. The average monthly cost of this group is displayed in Table XI-19a. With the 1115

demonstration, the cost of the State Plan services for this group will be less. Under the 1115 demonstration, the group must have other health insurance coverage to be eligible, and therefore we assume that the major medical costs for this group will be covered by their health insurance, even as they are permitted to pursue curative care. Since this group differs from the expanded group in qualifying for State Plan services not covered by insurance, we use the HCBS waiver group that is insured as a comparison group. Based on the experience of Medicaid “Buy Out” staff who track third party payment, they estimate that home health, professional therapy, medical supplies, and medical transportation are often not adequately covered by the child’s primary health insurance carrier. They estimate that Medicaid covers about 50 percent of the expenses for these services for the HCBS waiver group. Thus we estimate that Medicaid incurs about one third of the Medicaid costs for the services listed below for the HCBS waiver group and this figure will be comparable for the expanded hospice group. We also estimate that about 40 percent of the HCBS waiver group has insurance coverage. Therefore the projected average monthly cost to Medicaid for State Plan services for this group is displayed in Table XI-19b. The projected monthly cost of the new Promoting HOPE services that will be covered under the 1115 proposal will constitute additional costs (see Table XI-20).

Table XI–19B: Projected Average Monthly Cost for State Plan Services for Expanded Group - State Plan Hospice

With 1115 Demonstration		
Home-based services with limited insurance coverage for insured HCBS group	1999-2001 Medicaid Cost for Insured HCBS Group	Average Annual Cost for Insured HCBS Group
Home Health	387,345	129,115
Professional Therapy	5,486	1,829
Medical Supplies	63,607	21,202
Medical Transportation	3,728	1,243
Total	460,166	153,389
Insured HCBS group =40% of total days	17,666	5,889
average daily cost	26	26
average monthly cost	794	794

- c) **Projecting Cost of Expanded Services Offered to All Groups with the 1115 Demonstration** - The following table (Table XI-20) includes the new services to be offered to the children enrolled in the Promoting HOPE program, including the estimated unit cost and a projection of the average utilization for each of the three groups that will be covered under the 1115 Proposal. These services are designed to supplement the child’s primary insurance benefits and are in addition to other services. We assume the Expanded Group’s utilization of these services will be slightly higher than the Medicaid group, since the Medicaid group has access to a more comprehensive benefit package under Medicaid.

Table XI–20: Projecting Monthly Cost of Expanded Services for All Groups

Medicaid Group				
	Unit	Average Units/ month/child	Cost per Service	Average Monthly cost
Case Management	15 min	3	\$ 20	\$ 60
Palliative Care Consultation	Consult	0.25	200	50
Nursing/Other Visits	Visit	1	80	80
Ancillary Visits	Hour	5	18	90
Respite	Hour	8	40	320
Counseling	Visit	1	80	80
Medical Equipment/Supplies	Item	2	50	100
Pharmacy	Prescription	0	85	0
Transportation	Trip	0	25	0
Total				\$ 780
Expanded Group - State Plan Hospice with Insurance				
Case Management	15 min	3	\$ 20	\$ 60
Palliative Care Consultation	Consult	0.25	200	50
Nursing/Other Visits	Visit	2	80	160
Ancillary Visits	Hour	5	18	90
Respite	Hour	8	40	320
Counseling	Visit	1	80	80
Medical Equipment/Supplies	Item	2	50	100
Pharmacy	Prescription	0	85	0
Transportation	Trip	1	25	25
Total				\$ 885
Expanded Group - Non Hospice with Insurance				
Case Management	15 min	3	\$ 20	\$ 60
Palliative Care Consultation	Consult	0.25	200	50
Nursing/Other Visits	Visit	2	80	160
Ancillary Visits	Hour	5	18	90
Respite	Hour	8	40	320
Counseling	Visit	1	80	80
Medical Equipment/Supplies	Item	2	50	100
Pharmacy	Prescription	1	85	85
Transportation	Trip	1	25	25
Total				\$ 970

6. **Adjustments for Inflation** - The projected monthly cost of the State Plan and Expanded Services for the Medicaid group, and both Expanded Groups is adjusted for an 8 percent inflation factor per year from the average base year of CY 2001 to the beginning of state fiscal year 2004. A 12 percent inflation factor is calculated in 2004 to adjust from a calendar year to the start of the state fiscal year July 1, 2004 (18 month period) when we hope to begin the program. This inflation factor is lower than what Medicaid has experienced in the last few years, but corresponds to the amount that was allowed in the recently approved Utah 1115 for the Primary Care Network Program.

Table XI–21: Projected Monthly Cost of State Plan Services Adjusted for Inflation

With 1115 Demonstration - Medicaid Group					
	Neoplasm	Congenital	Perinatal	Other	All
Projected Monthly Cost*	6,788	4,063	13,986	5,264	6,808
Adjusted for Inflation					
Inflation 8.0% - CY2002	7,331	4,388	15,105	5,685	7,353
Inflation 8.0% - CY2003	7,918	4,740	16,314	6,140	7,941
Inflation 12.0% - FY2004 (Start Year adjust to FY)	8,868	5,308	18,271	6,876	8,894
Inflation 8.0% - FY2005	9,577	5,733	19,733	7,426	9,606
Inflation 8.0% - FY2006	10,343	6,192	21,312	8,020	10,374
Inflation 8.0% - FY2007	11,171	6,687	23,017	8,662	11,204
Inflation 8.0% - FY2008	12,065	7,222	24,858	9,355	12,100
Without 1115 Demonstration - Expanded Group - Hospice State Plan					
Adjusted Projected Cost					3,691
Adjusted for Inflation					
Inflation 8.0% - 2002					3,986
Inflation 8.0% - 2003					4,305
Inflation 12.0% - FY2004 (Start Year adjust to FY)					4,821
Inflation 8.0% - FY2005					5,207
Inflation 8.0% - FY2006					5,623
Inflation 8.0% - FY2007					6,073
Inflation 8.0% - FY2008					6,559
With 1115 Demonstration - Expanded Group - Hospice State Plan					
Adjusted Projected Cost					794
Adjusted for Inflation					
Inflation 8.0% - 2002					858
Inflation 8.0% - 2003					927
Inflation 12.0% - FY2004 (Start Year adjust to FY)					1,038
Inflation 8.0% - FY2005					1,121
Inflation 8.0% - FY2006					1,211
Inflation 8.0% - FY2007					1,307
Inflation 8.0% - FY2008					1,412

Table XI–22: Monthly Cost of Expanded Services By Group Adjusted for Inflation

	Medicaid Group	Expanded Group
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Adjusted for Inflation		Hospice	Non-Hospice
Inflation 8.0% - CY2002	780	885	970
Inflation 8.0% - CY2003	842	956	1048
Inflation 12.0% - FY2004 (Start Year adjust to FY)	943	1070	1173
Inflation 8.0% - FY2005	1019	1156	1267
Inflation 8.0% - FY2006	1100	1249	1369
Inflation 8.0% - FY2007	1189	1349	1478
Inflation 8.0% - FY2008	1284	1456	1596

7. Projecting Fees to Be Collected - One of the major the program goals is to make support services accessible to all children in Utah who have a life-threatening conditions. In keeping with the program principles, to use public monies effectively and by extension to ensure that families participate in the cost of care to the extent of their ability, we will charge a monthly participation fee to the Expanded Group that does not qualify under the proposed Hospice-State Plan Amendment. The fee will be based on a sliding fee schedule that will escalate sharply for families at or above 600% of poverty. The fee will help achieve budget neutrality and help ensure that families who participate in the program will value the services offered. For ease of administration, we will determine family income group based on gross family income as reported on the family's latest income tax return, and size of family household. A deduction will be allowed for paid health insurance premiums. Based on an array of income groups we estimate that we will collect about 8 percent of the average monthly cost of the expanded services (Table XI -24, sliding fee schedule). The schedule currently shows the income brackets for a family of three (average household size in Utah). This schedule will be adapted and simplified for other size families before the implementation of the program.

F. Estimated Costs for the Five-Year 1115 Demonstration Program and Budget Neutrality

The estimated cost for each year of the program is delineated in the tables on the following pages. For each year we have calculated the cost with and without the waiver authority of the proposed 1115 Proposal, and with the approved authority of the Section 1115 Proposal for the Promoting HOPE program, using the projected costs, months, distribution of cases, and inflation factors described in the previous section. We have used the same number of Medicaid State Plan eligibles (including hospice state plan group) in computing the with and without demonstration costs. Base year costs for Medicaid expenditures without the 1115 demonstration are included for each year. As indicated in the beginning of this section, we believe the projections are conservative and will result in a budget neutral program.

Table XI - 23: Summary of Promoting HOPE Costs with and Without the 1115 Demonstration

Year	Projected Enrollment	Without 1115 Demonstration	With 1115 Demonstration	Annual Savings	Cumulative Savings
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1	120	\$9,760,605	\$9,718,253	\$42,352	
2	231	\$12,549,122	\$12,395,429	\$153,693	\$196,045
3	252	\$15,473,007	\$15,272,340	\$200,667	\$396,712
4	309	\$18,372,387	\$18,159,912	\$212,475	\$609,187
5	327	\$20,384,050	\$20,136,464	\$247,586	\$856,772

Table XI-24: Sliding Fee Schedule and Projected Revenues for Average Year for Non-Hospice Expanded Group

	Income Range		Percent of Poverty [based on maximum income for range]	Fee / Cost [%]	Projected Average Annual Cost [8.7 mos.]	Projected Monthly Fee	Average Annual Fee as Percent of Annual Income	Distribution of Utah Households by Income [CY 2000]	Expected Distribution by Household Income of Expanded Group [Non Hospice]	Expected Child-Months of Expanded Group [Non Hospice] Utilization by Household Income	Projected Fee Revenues	Revenue per child month
Covered by Medicaid and CHIP	Under	\$ 5,000	35%	0	\$ -	\$ -	0.0%	5.3%		0		
	\$ 5,001	\$ 10,000	71%	0	\$ -	\$ -	0.0%	5.6%		0		
	\$ 10,001	\$ 15,000	106%	0	\$ -	\$ -	0.0%	6.3%		0		
	\$ 15,001	\$ 20,000	141%	0	\$ -	\$ -	0.0%	6.6%		0		
	\$ 20,001	\$ 25,000	177%	0	\$ -	\$ -	0.0%	6.4%		0		
Expanded Group [Non Hospice]	\$ 25,001	\$ 30,000	212%	2%	\$ 212.62	\$ 24.44	0.8%	6.0%	8.8%	38.4	\$ 938.03	\$ 24.44
	\$ 30,001	\$ 40,000	283%	3%	\$ 318.93	\$ 36.66	0.9%	11.9%	17.5%	76.1	\$ 2,790.64	\$ 36.66
	\$ 40,001	\$ 50,000	353%	5%	\$ 531.55	\$ 61.10	1.2%	10.9%	16.0%	69.7	\$ 4,260.22	\$ 61.10
	\$ 50,001	\$ 75,000	530%	8%	\$ 850.48	\$ 97.76	1.4%	20.5%	30.1%	131.1	\$12,819.74	\$ 97.76
	\$ 75,001	\$ 100,000	707%	15%	\$ 1,594.65	\$ 183.29	1.8%	9.6%	14.1%	61.4	\$11,256.35	\$ 183.29
	\$ 100,001	\$ 250,000	3707%	35%	\$ 3,720.85	\$ 427.68	2.1%	9.1%	13.4%	58.2	\$24,896.86	\$ 427.68
	Over	\$ 250,000	Not Likely to Participate						1.8%			
	Total								100.0%	100.0%		
	Utah Households Likely to Participate in Expanded [Non Hospice] Program based on income and Medicaid/CHIP Eligibility [%]								68.0%			
	[Enter] Number of children using the program for an average of 8.7 months									50		
	Total child-months of Utilization in Year One								435	435.0		
	Total Projected Revenues										\$56,961.84	

Table XI-25A: Year One Budget Neutrality Projections for the Promoting HOPE Program

Current State Plan Services									
CY1999-2001 Average		No. Children	% by DX	Average Months	Total Months	Average Monthly Cost	Total Annual Cost		
State Plan Eligibles	Neoplasm	37	15.6%	7.4	273.8	8,030	2,198,614		
	Congenital	88	37.0%	6.4	565.3	5,500	3,109,333		
	Perinatal	55	22.9%	5.8	317.1	21,852	6,928,541		
	Other	58	24.5%	7.9	460.8	6,851	3,157,169		
	Total	239	100.0%	6.8	1617.0	9,520	15,393,657		
Base Year Monthly Adjusted						Average Monthly Cost	Inflation 12% - 2002	Inflation 8% - 2003	Inflation 8% - 2004
State Plan Eligibles	Neoplasm					8,030	8,994	9,713	10,490
	Congenital					5,500	6,160	6,653	7,185
	Perinatal					21,852	24,474	26,432	28,547
	Other					6,851	7,673	8,287	8,950
	Average					9,520	10,662	11,515	12,436
FY 2004 Year One - Cost Projections - Without 1115 Demonstration*									
State Plan Eligibles	Dx Group	No. Children	% by Dx	Average Months	Total Months	Average Monthly Cost	Total Annual Cost		
	Neoplasm	35	28.8%	7.4	255.3	10,490	2,678,268		
	Congenital	38	31.3%	6.4	240.4	7,185	1,726,960		
	Perinatal	21	17.3%	5.8	120.2	28,547	3,430,595		
	Other	27	22.7%	7.9	215.1	8,950	1,924,783		
	Total	120	100.0%	6.9	830.9	11,747	9,760,605		
FY 2004 Year One - Cost Projections - With 111 Demonstration*									
State Plan Services									
State Plan Eligibles		No. Children	% by DX	Average Months	Total Months	Average Monthly Cost	Total Annual Cost		
	Neoplasm	35	28.8%	8.9	307.1	8,868	2,722,988		
	Congenital	38	31.3%	7.7	289.2	5,308	1,535,050		
	Perinatal	21	17.3%	7.0	144.3	18,271	2,636,842		
	Other	27	22.7%	9.6	261.3	6,876	1,797,047		
	Sub Total	120	100.0%	8.3	1001.9	8,675	8,691,927		
New Expanded Services									
	All Dx Groups	120		8.3	1087.8	943	1,026,326		
	Total Costs						9,718,253		
Year One	Annual Savings						42,352		

* The number of Medicaid (State Plan eligibles) With and Without 1115 Demonstration are the same for comparability.

Table XI-25B: Year Two Budget Neutrality Projections for the Promoting HOPE Program

FY 2004- Base Year Adjusted for Inflation							
Base Year Monthly Adjusted						Adjusted Monthly FY2004	Inflation 8% - FY2005
State Plan Eligibles	Neoplasm					10,490	11,329
	Congenital					7,185	7,760
	Perinatal					28,547	30,830
	Other					8,950	9,666
	Average					12,436	13,431
FY 2005 Year Two Cost Projections - Without 1115 Demonstration*							
	Dx Group	No. Children	% by Dx	Average Months	Total Months	Average Monthly Cost	Total Annual Cost
State Plan Eligibles	Neoplasm	38	28.8%	7.4	278.7	11,329	3,157,678
	Congenital	41	31.3%	6.4	262.4	7,760	2,036,086
	Perinatal	23	17.3%	5.8	131.2	30,830	4,044,672
	Other	30	22.7%	7.9	234.8	9,666	2,269,319
	SubTotal	131	100.0%	6.9	907.1	12,687	11,507,753
Expanded Group - State Plan Hospice	Neoplasm	14	28.8%	4.0	57.5		
	Congenital	16	31.3%	4.0	62.6		
	Perinatal	9	17.3%	4.0	34.5		
	Other	11	22.7%	4.0	45.4		
	SubTotal	50	100.0%	4.0	200.0	5,207	1,041,369
Expanded Group - Non Hospice	Neoplasm						
	Congenital						
	Perinatal						
	Other						
	SubTotal	50		0	0	0	0
Total		231			1,107.1		12,549,122
FY 2005 Year Two - Cost Projections - With 1115 Demonstration*							
State Plan Eligibles	State Plan Services						
	Neoplasm	38	28.8%	8.9	335.2	9,577	3,210,403
	Congenital	41	31.3%	7.7	315.7	5,733	1,809,824
	Perinatal	23	17.3%	7.0	157.5	19,733	3,108,837
	Other	30	22.7%	9.6	285.3	7,426	2,118,718
	SubTotal	131	100.0%	8.3	1093.7	9,369	10,247,782
Expanded Group - State Plan Hospice	Expanded Services						
		131		8.3	1093.7	1,019	1,114,485
	State Plan Services						
	Neoplasm	14	28.8%	4.8	69.0		0
	Congenital	16	31.3%	4.8	75.1		0
	Perinatal	9	17.3%	4.8	41.4		0
Expanded Group - Non Hospice	Other	11	22.7%	4.8	54.4		0
	SubTotal	50	100.0%	4.8	240.0	1,121	269,015
	Expanded Services						
		50		4.8	240.0	1,156	277,473
	State Plan Services						
	Neoplasm						
	Congenital						
	Perinatal						
	Other						
	SubTotal	50				0	0
Expanded Group - Non Hospice	Expanded Services						
		50		8.3	417.5	1,267	528,993
	Fee 8% offset					8.0%	(42,319)
	SubTotal	50					486,674
	Total	231					12,395,429
Year Two	Annual Savings						153,693
	Prior Year Savings						42,352
	Cumulative Savings						196,045

* The number of Medicaid (State Plan eligibles) With and Without 1115 Demonstration are the same for comparability.

Table XI-25C: Year Three Budget Neutrality Projections for Promoting HOPE Program

		FY 2004- Base Year Adjusted for Inflation					
Base Year Monthly Adjusted				Adjusted Monthly FY2004	Inflation 8% - FY2005	Inflation 8% - FY2006	
State Plan Eligibles	Neoplasm			10,490	11,329	12,236	
	Congenital			7,185	7,760	8,381	
	Perinatal			28,547	30,830	33,297	
	Other			8,950	9,666	10,439	
	Average			12,436	13,431	14,506	
FY 2006 Year Three Cost Projections - Without 1115 Demonstration*							
	Dx Group	No. Children	% by Dx	Average Months	Total Months	Average Monthly Cost	Total Annual Cost
State Plan Eligibles	Neoplasm	43	28.8%	7.4	321.3	12,236	3,930,947
	Congenital	47	31.3%	6.4	302.4	8,381	2,534,693
	Perinatal	26	17.3%	5.8	151.2	33,297	5,035,153
	Other	34	22.7%	7.9	270.6	10,439	2,825,042
	SubTotal	151	100.0%	6.9	1045.6	13,702	14,325,835
Expanded Group - State Plan Hospice	Neoplasm	15	28.8%	4.0	58.7		0
	Congenital	16	31.3%	4.0	63.8		0
	Perinatal	9	17.3%	4.0	35.2		0
	Other	12	22.7%	4.0	46.3		0
	SubTotal	51	100.0%	4.0	204.0	5,623	1,147,172
Expanded Group - Non Hospice	Neoplasm						
	Congenital						
	Perinatal						
	Other						
	SubTotal	50		0	0	0	0
Total		252			1,249.6		15,473,007
FY 2006 Year Three - Cost Projections - With 1115 Demonstration*							
State Plan Eligibles	State Plan Services						
	Neoplasm	43	28.8%	8.9	386.4	10,343	3,996,584
	Congenital	47	31.3%	7.7	363.9	6,192	2,253,024
	Perinatal	26	17.3%	7.0	181.6	21,312	3,870,146
	Other	34	22.7%	9.6	328.9	8,020	2,637,562
	SubTotal	151	100.0%	8.3	1260.7	10,119	12,757,315
Expanded Group - State Plan Hospice	Expanded Services						
		151		8.3	1260.7	1,100	1,387,407
	State Plan Services						
	Neoplasm	15	28.8%	4.8	70.4	0	0
	Congenital	16	31.3%	4.8	76.6	0	0
	Perinatal	9	17.3%	4.8	42.3	0	0
	Other	12	22.7%	4.8	55.5	0	0
	SubTotal	51	100.0%	4.8	244.8	1,211	296,347
Expanded Group - Non Hospice	Expanded Services						
		51		4.8	244.8	1,249	305,664
	State Plan Services						
	Neoplasm						
	Congenital						
	Perinatal						
	Other						
	SubTotal	50				0	0
Expanded Group - Non Hospice	Expanded Services						
		50		8.3	417.5	1,369	571,313
	Fee 8% offset					8.0%	(45,705)
	SubTotal	50					525,608
	Total	252					15,272,340
Year Three	Annual Savings						200,667
	Prior Years' Savings						196,045
	Cumulative Savings						396,712

* The number of Medicaid (State Plan eligibles) With and Without 1115 Demonstration are the same for comparability.

Table XI-25D: Year Four Budget Neutrality Projections for the Promoting HOPE Program

FY2004 - Base Year Adjusted for Inflation							
Base Year Monthly Adjusted						Adjusted Monthly FY2004	Inflation 8% - 2005
							Inflation 8% - 2006
							Inflation 8% - 2007
							Inflation 8% - 2007
	Neoplasm					10,490	11,329
	Congenital					7,185	7,760
	Perinatal					28,547	30,830
	Other					8,950	9,666
State Plan Eligibles	Average					12,436	13,431
							14,506
							15,666
FY 2007 Year Four - Cost Projections - Without 1115 Demonstration*							
	Dx Group	No. Children	% by Dx	Average Months	Total Months	Average Monthly Cost	Total Annual Cost
State Plan Eligibles	Neoplasm	47	28.8%	7.4	344.7	13,215	4,554,692
	Congenital	51	31.3%	6.4	324.5	9,051	2,936,887
	Perinatal	28	17.3%	5.8	162.2	35,961	5,834,108
	Other	37	22.7%	7.9	290.3	11,274	3,273,307
	SubTotal	162	100.0%	6.9	1121.7	14,798	16,598,994
Expanded Group - State Plan Hospice	Neoplasm	21	28.8%	4.0	84.0		0
	Congenital	23	31.3%	4.0	91.4		0
	Perinatal	13	17.3%	4.0	50.4		0
	Other	17	22.7%	4.0	66.2		0
	SubTotal	73	100.0%	4.0	292.0	6,073	1,773,392
Expanded Group - Non Hospice	Neoplasm						
	Congenital						
	Perinatal						
	Other						
	SubTotal	74		0	0	0	0
Total		309			1,413.7		18,372,387
FY 2007 Year Four - Cost Projections - With 1115 Demonstration*							
State Plan Eligibles	State Plan Services						
	Neoplasm	47	28.8%	8.9	414.5	11,171	4,630,744
	Congenital	51	31.3%	7.7	390.4	6,687	2,610,524
	Perinatal	28	17.3%	7.0	194.8	23,017	4,484,243
	Other	37	22.7%	9.6	352.8	8,662	3,056,078
	SubTotal	162	100.0%	8.3	1352.6	10,929	14,781,589
Expanded Group - State Plan Hospice	Expanded Services						
		162		8.3	1352.6	1,189	1,607,554
	State Plan Services						
	Neoplasm	21	28.8%	4.8	100.7		0
	Congenital	23	31.3%	4.8	109.7		0
	Perinatal	13	17.3%	4.8	60.5		0
Expanded Group - Non Hospice	Other	17	22.7%	4.8	79.5		0
	SubTotal	73	100.0%	4.8	350.4	1,307	458,118
	Expanded Services						
		73		4.8	350.4	1,349	472,520
	State Plan Services						
	Neoplasm						
	Congenital						
	Perinatal						
	Other						
	SubTotal					0	0
Expanded Group - Non Hospice	Expanded Services						
		74		8.3	617.8	1,478	913,186
	Fee 8% offset					8.0%	(73,055)
	SubTotal	74		8.3			840,131
Total		309					18,159,912
Year Four							
							212,475
							396,712
							609,187

* The number of Medicaid (State Plan eligibles) With and Without 1115 Demonstration are the same for comparability.

Table XI-25E: Year Five Budget Neutrality Projections for the Promoting HOPE Program

Base Year Monthly Adjusted		FY2004- Base Year Adjusted for Inflation					
		Adjusted Monthly FY2004	Inflation 8% - 2005	Inflation 8% - 2006	Inflation 8% - 2007	Inflation 8% - 2008	
State Plan Eligibles	Neoplasm	10,490	11,329	12,236	13,215	14,272	
	Congenital	7,185	7,760	8,381	9,051	9,775	
	Perinatal	28,547	30,830	33,297	35,961	38,838	
	Other	8,950	9,666	10,439	11,274	12,176	
	Average	12,436	13,431	14,506	15,666	16,919	
FY 2008 Year Five - Cost Projections - Without 1115 Demonstration*							
	Dx Group	No. Children	% by Dx	Average Months	Total Months	Average Monthly Cost	Total Annual Cost
State Plan Eligibles	Neoplasm	47	28.8%	7.4	351.1	14,272	5,010,161
	Congenital	52	31.3%	6.4	330.5	9,775	3,230,576
	Perinatal	28	17.3%	5.8	165.2	38,838	6,417,519
	Other	37	22.7%	7.9	295.7	12,176	3,600,638
	SubTotal	165	100.0%	6.9	1142.5	15,982	18,258,894
Expanded Group - State Plan Hospice	Neoplasm	23	28.8%	4.0	93.2		0
	Congenital	25	31.3%	4.0	101.4		0
	Perinatal	14	17.3%	4.0	55.9		0
	Other	18	22.7%	4.0	73.5		0
	SubTotal	81	100.0%	4.0	324.0	6,559	2,125,156
Expanded Group - Non Hospice	Neoplasm						
	Congenital						
	Perinatal						
	Other						
	SubTotal	81		0	0	0	0
Total		327			1,466.5		20,384,050
FY 2008 Year Five - Cost Projections - With 1115 Demonstration*							
State Plan Eligibles	State Plan Services						
	Neoplasm	47	28.8%	8.9	422.2	12,065	5,093,818
	Congenital	52	31.3%	7.7	397.6	7,222	2,871,576
	Perinatal	28	17.3%	7.0	198.4	24,858	4,932,667
	Other	37	22.7%	9.6	359.3	9,355	3,361,686
	SubTotal	165	100.0%	8.3	1377.6	11,803	16,259,747
Expanded Group - State Plan Hospice	Expanded Services						
		165		8.3	1377.6	1,284	1,768,309
	State Plan Services						
	Neoplasm	23	28.8%	4.8	111.8		0
	Congenital	25	31.3%	4.8	121.7		0
	Perinatal	14	17.3%	4.8	67.1		0
	Other	18	22.7%	4.8	88.2		0
	SubTotal	81	100.0%	4.8	388.8	1,412	548,988
Expanded Services							
	81		4.8	388.8	1,456	566,248	
Expanded Group - Non Hospice	State Plan Services						
	Neoplasm						
	Congenital						
	Perinatal						
	Other						
	SubTotal					0	0
Expanded Services							
	81		8.3	676.3	1,596	1,079,534	
Fee 8% offset						(86,363)	
SubTotal		81				993,172	
Total		327				20,136,464	
Year Five	Annual Savings						247,586
	Prior Years' Savings						609,187
	Cumulative Savings						856,772

* The number of Medicaid (State Plan eligibles) With and Without 11115 Demonstration are the same for comparability.

G. Estimated Administrative Costs for the Five-Year 1115 Program and Budget Neutrality

We have projected the estimated administrative costs of the program based on projected average enrollment per year. We understand that the administrative costs do not count towards budget neutrality. See Tables XI-27A-E for the projections of estimated cost of the administration of the program is included in the following tables by year. As the size of the monthly average caseload grows, we will add additional administrative staff. The estimated caseload for the Care Coordinator is about 60 cases, for the Outreach Coordinator and Eligibility Worker, the estimated caseload is 100 to 150 cases, and for the Insurance Navigator, the range is from 120 cases to 180.

We believe these estimates are reasonable. When administrative costs are calculated as a percentage of the total program cost, the administrative cost are on average only slightly higher than 2 % of the program cost with the waiver.

Table XI–26: Administrative Cost as Percentage of Program Costs

Year	Total Program Cost	Total Administrative Cost	Admin. Cost as % of Total Program Cost
1	\$9,760,605	217,496	2.2%
2	\$12,549,122	302,236	2.4%
3	\$15,473,007	306,770	2.0%
4	\$18,372,387	366,312	2.0%
5	\$20,384,050	371,807	1.8%

Table XI-27A: Estimated Base Year and Year One Administrative Expenditures for the Promoting HOPE Program

FY2004 -Year One: Projected Monthly Enrollment = 67	Hourly	Base Salary	Benefits	Base Salary and Benefits	Percent Time	Total Annual Expenses	State Match Share		Federal Share	
							%	\$	%	\$
Personnel										
Promoting HOPE Administrator	\$19.97	\$41,540	\$15,370	\$56,910	0.50	\$28,455	50%	\$14,227	50%	\$14,227
Secretarial Support	\$13.53	\$28,140	\$10,412	\$38,552	0.10	\$3,855	50%	\$1,928	50%	\$1,928
Outreach Coordinator	\$17.39	\$36,180	\$13,387	\$49,567	0.50	\$24,783	50%	\$12,392	50%	\$12,392
Care Coordinator	\$23.19	\$48,240	\$17,849	\$66,089	1.00	\$72,000	25%	\$18,000	75%	\$54,000
Insurance Navigator	\$17.39	\$36,180	\$13,387	\$49,567	0.50	\$24,783	50%	\$12,392	50%	\$12,392
Eligibility Worker	\$15.56	\$32,365	\$11,975	\$44,340	0.50	\$22,170	50%	\$11,085	50%	\$11,085
Subtotal					3.10	\$176,047	39.8%	\$70,023	53.9%	\$94,938
Other Direct Costs										
Supplies						\$1,500		\$597		\$809
Duplicating/Postage						\$2,000		\$796		\$1,079
In-State Travel						\$4,000		\$1,591		\$2,157
Out-of-State Travel/Workshops						\$5,000		\$1,989		\$2,696
Educational Materials						\$2,000		\$796		\$1,079
Provider Training/Advisory Council						\$3,000		\$1,193		\$1,618
Equipment						\$500		\$199		\$270
Subtotal						\$18,000	39.8%	\$7,160	53.9%	\$9,707
Consultant/Contractual										
Evaluation						\$2,500	50%	\$1,250	50.0%	\$1,250
Subtotal						\$2,500		\$1,250		\$1,250
Total						\$196,547		\$78,433		\$105,895
Indirect Costs 11.9% Personnel						\$20,950		\$8,333		\$11,298
Grand Total						\$217,496		\$86,766		\$117,193

Table XI-27B: Estimated Year Two Administrative Expenditures for the Promoting HOPE Program

FY2005 -Year Two- Projected Monthly Enrollment = 129	Hourly	Base Salary	Benefits	Base Salary and Benefits	Percent Time	Total Annual Expenses	Adjusted Inflation & 1.5 COLA	State Match Share		Federal Share	
								%	\$	%	\$
Personnel											
Administrator & Grant Project Director	\$19.97	\$41,540	\$15,370	\$56,910	0.50	\$28,455	\$28,882	50%	\$14,441	50%	\$14,441
Secretarial Support	\$13.53	\$28,140	\$10,412	\$38,552	0.10	\$3,855	\$3,913	50%	\$1,957	50%	\$1,957
Outreach Coordinator	\$17.39	\$36,180	\$13,387	\$49,567	1.00	\$49,567	\$50,310	50%	\$25,155	50%	\$25,155
Care Coordinator	\$23.19	\$48,240	\$17,849	\$66,089	2.00	\$72,000	\$73,080	25%	\$18,270	75%	\$54,810
Insurance Navigator	\$17.39	\$36,180	\$13,387	\$49,567	1.00	\$49,567	\$50,310	50%	\$25,155	50%	\$25,155
Eligibility Worker	\$15.56	\$32,365	\$11,975	\$44,340	1.00	\$44,340	\$45,005	50%	\$22,503	50%	\$22,503
Subtotal					5.60	\$247,783	\$251,500	42.7%	\$107,480	57.3%	\$144,020
Other Direct Costs											
Supplies						\$1,500	\$1,523		\$651		\$872
Duplicating/Postage						\$2,000	\$2,030		\$868		\$1,162
In-State Travel						\$4,000	\$4,060		\$1,735		\$2,325
Out-of-State Travel/Workshops						\$5,000	\$5,075		\$2,169		\$2,906
Educational Materials						\$2,000	\$2,030		\$868		\$1,162
Provider Training/Advisory Council						\$3,000	\$3,045		\$1,301		\$1,744
Equipment						\$500	\$508		\$217		\$291
Subtotal						\$18,000	\$18,270	42.7%	\$7,808	57.3%	\$10,462
Consultant/Contractual											
Evaluation						\$2,500	\$2,538	50%	\$1,269	50.0%	\$1,269
Subtotal						\$2,500	\$2,538		\$1,269		\$1,269
Total						\$268,283	\$272,308		\$116,557		\$155,751
Indirect Costs 11.9% Personnel						\$29,486	\$29,929		\$12,790		\$17,138
Grand Total						\$297,770	\$302,236		\$129,347		\$172,889

Table XI-27C: Estimated Year Three Administrative Expenditures for the Promoting HOPE Program

CY 2006 Year Three - Projected Monthly Enrollment = 140	Hourly	Base Salary	Benefits	Base Salary and Benefits	Percent Time	Total Annual Expenses	Adjusted Inflation & 1.5% COLA (FY2005)	Adjusted Inflation & 1.5% COLA (FY2006)	State Match Share		Federal Share	
									%	\$	%	\$
Personnel												
Administrator	\$19.97	\$41,540	\$15,370	\$56,910	0.50	\$28,455	\$28,882	\$29,315	50%	\$14,657	50%	\$14,657
Secretarial Support	\$13.53	\$28,140	\$10,412	\$38,552	0.10	\$3,855	\$3,913	\$3,972	50%	\$1,986	50%	\$1,986
Outreach Coordinator	\$17.39	\$36,180	\$13,387	\$49,567	1.00	\$49,567	\$50,310	\$51,065	50%	\$25,532	50%	\$25,532
Care Coordinator	\$23.19	\$48,240	\$17,849	\$66,089	2.00	\$72,000	\$73,080	\$74,176	25%	\$18,544	75%	\$55,632
Insurance Navigator	\$17.39	\$36,180	\$13,387	\$49,567	1.00	\$49,567	\$50,310	\$51,065	50%	\$25,532	50%	\$25,532
Eligibility Worker	\$15.56	\$32,365	\$11,975	\$44,340	1.00	\$44,340	\$45,005	\$45,680	50%	\$22,840	50%	\$22,840
Subtotal					5.60	\$247,783	\$251,500	\$255,273	42.7%	\$109,092	57.3%	\$146,180
Other Direct Costs												
Supplies						\$1,500	\$1,523	\$1,545		\$660		\$885
Duplicating/Postage						\$2,000	\$2,030	\$2,060		\$881		\$1,180
In-State Travel						\$4,000	\$4,060	\$4,121		\$1,761		\$2,360
Out-of-State Travel/Workshops						\$5,000	\$5,075	\$5,151		\$2,201		\$2,950
Educational Materials						\$2,000	\$2,030	\$2,060		\$881		\$1,180
Provider Training/Advisory Council						\$3,000	\$3,045	\$3,091		\$1,321		\$1,770
Equipment						\$500	\$508	\$515		\$220		\$295
Subtotal						\$18,000	\$18,270	\$18,544	42.7%	\$7,925	57.3%	\$10,619
Consultant/Contractual												
Evaluation						\$2,500	\$2,538	\$2,576	50%	\$1,288	50.0%	\$1,288
Subtotal						\$2,500	\$2,538	\$2,576		\$1,288		\$1,288
Total						\$268,283	\$272,308	\$276,392		\$118,305		\$158,087
Indirect Costs 11.9% Personnel						\$29,486	\$29,929	\$30,377		\$12,982		\$17,395
Grand Total						\$297,770	\$302,236	\$306,770		\$131,287		\$175,483

Table XI-27D: Estimated Year Four Administrative Expenditures for the Promoting HOPE Program

CY 2007 Year Four - Projected Monthly Enrollment = 172	Hourly	Base Salary	Benefits	Base Salary + Benefits	Percent Time	Total Annual Expenses	Adjusted Inflation & 1.5 COLA (FY2005)	Adjusted Inflation & 1.5 COLA (FY2006)	Adjusted Inflation & 1.5 COLA (FY2007)	State Match Share		Federal Share	
										%	\$	%	\$
Personnel													
Administrator	\$19.97	\$41,540	\$15,370	\$56,910	0.50	\$28,455	\$28,882	\$29,315	\$29,755	50%	\$14,877	50%	\$14,877
Secretarial Support	\$13.53	\$28,140	\$10,412	\$38,552	0.10	\$3,855	\$3,913	\$3,972	\$4,031	50%	\$2,016	50%	\$2,016
Outreach Coordinator	\$17.39	\$36,180	\$13,387	\$49,567	1.50	\$74,350	\$75,465	\$76,597	\$77,746	50%	\$38,873	50%	\$38,873
Care Coordinator	\$23.19	\$48,240	\$17,849	\$66,089	3.00	\$72,000	\$73,080	\$74,176	\$75,289	25%	\$18,822	75%	\$56,467
Insurance Navigator	\$17.39	\$36,180	\$13,387	\$49,567	1.00	\$49,567	\$50,310	\$51,065	\$51,831	50%	\$25,915	50%	\$25,915
Eligibility Worker	\$15.56	\$32,365	\$11,975	\$44,340	1.50	\$66,510	\$67,508	\$68,520	\$69,548	50%	\$34,774	50%	\$34,774
Subtotal					7.60	\$294,737	\$299,158	\$303,645	\$308,200	44.6%	\$135,278	56.9%	\$172,922
Other Direct Costs													
Supplies						\$1,500	\$1,523	\$1,545	\$1,569		\$699		\$893
Duplicating/Postage						\$2,000	\$2,030	\$2,060	\$2,091		\$932		\$1,191
In-State Travel						\$4,000	\$4,060	\$4,121	\$4,183		\$1,863		\$2,382
Out-of-State Travel/Workshops						\$5,000	\$5,075	\$5,151	\$5,228		\$2,329		\$2,978
Educational Materials						\$2,000	\$2,030	\$2,060	\$2,091		\$932		\$1,191
Provider Training/Advisory Council						\$3,000	\$3,045	\$3,091	\$3,137		\$1,398		\$1,787
Equipment						\$500	\$508	\$515	\$523		\$233		\$298
Subtotal						\$18,000	\$18,270	\$18,544	\$18,822	44.6%	\$8,386	56.9%	\$10,719
Consultant/Contractual													
Evaluation						\$2,500	\$2,538	\$2,576	\$2,614	50%	\$1,250	50.0%	\$1,250
Subtotal						\$2,500	\$2,538	\$2,576	\$2,614		\$1,250		\$1,250
Total						\$315,237	\$319,965	\$324,765	\$329,636		\$144,913		\$184,891
Indirect Costs 11.9% Personnel						\$35,074	\$35,600	\$36,134	\$36,676		\$16,098		\$20,578
Grand Total						\$350,310	\$355,565	\$360,898	\$366,312		\$161,011		\$205,469

Table XI-27E: Estimated Year Five Administrative Expenditures for the Promoting HOPE Program

CY 2008 Year Five - Projected Monthly Enrollment = 182	Hourly	Base Salary	Benefits	Base Salary + Benefits	Percent Time	Total Annual Expenses	Adjusted Inflation & 1.5 COLA (FY2005)	Adjusted Inflation & 1.5 COLA (FY2006)	Adjusted Inflation & 1.5 COLA (FY2007)	Adjusted Inflation & 1.5 COLA (FY2008)	State Match Share		Federal Share	
											%	\$	%	\$
Personnel														
Administrator	\$19.97	\$41,540	\$15,370	\$56,910	0.50	\$28,455	\$28,882	\$29,315	\$29,755	\$30,201	50%	\$15,100	50%	\$15,100
Secretarial Support	\$13.53	\$28,140	\$10,412	\$38,552	0.10	\$3,855	\$3,913	\$3,972	\$4,031	\$4,092	50%	\$2,046	50%	\$2,046
Outreach Coordinator	\$17.39	\$36,180	\$13,387	\$49,567	1.50	\$74,350	\$75,465	\$76,597	\$77,746	\$78,912	50%	\$39,456	50%	\$39,456
Care Coordinator	\$23.19	\$48,240	\$17,849	\$66,089	3.00	\$72,000	\$73,080	\$74,176	\$75,289	\$76,418	25%	\$19,105	75%	\$57,314
Insurance Navigator	\$17.39	\$36,180	\$13,387	\$49,567	1.00	\$49,567	\$50,310	\$51,065	\$51,831	\$52,608	50%	\$26,304	50%	\$26,304
Eligibility Worker	\$15.56	\$32,365	\$11,975	\$44,340	1.50	\$66,510	\$67,508	\$68,520	\$69,548	\$70,591	50%	\$35,296	50%	\$35,296
Subtotal					7.60	294,736.66	299,157.70	303,645.07	308,199.75	312,822.74	45.2%	\$137,307	57.8%	\$175,516
Other Direct Costs														
Supplies						\$1,500	\$1,523	\$1,545	\$1,569	\$1,592		\$720		\$920
Duplicating/Postage						\$2,000	\$2,030	\$2,060	\$2,091	\$2,123		\$960		\$1,227
In-State Travel						\$4,000	\$4,060	\$4,121	\$4,183	\$4,245		\$1,920		\$2,454
Out-of-State Travel/Workshops						\$5,000	\$5,075	\$5,151	\$5,228	\$5,307		\$2,400		\$3,067
Educational Materials						\$2,000	\$2,030	\$2,060	\$2,091	\$2,123		\$960		\$1,227
Provider Training/Advisory Council Equipment						\$3,000	\$3,045	\$3,091	\$3,137	\$3,184		\$1,440		\$1,840
Subtotal						\$500	\$508	\$515	\$523	\$531		\$240		\$307
Subtotal						\$18,000	\$18,270	\$18,544	\$18,822	\$19,105	45.2%	\$8,639	57.8%	\$11,043
Consultant/Contractual														
Evaluation						\$2,500	\$2,538	\$2,576	\$2,614	\$2,653	50%	\$1,327	50.0%	\$1,327
Subtotal						\$2,500	\$2,538	\$2,576	\$2,614	\$2,653		\$1,327		\$1,327
Total						\$315,237	\$319,965	\$324,765	\$329,636	\$334,581		\$147,273		\$187,886
Indirect Costs 11.9% Personnel						\$35,074	\$35,600	\$36,134	\$36,676	\$37,226		\$16,340		\$20,886
Grand Total						\$350,310	\$355,565	\$360,898	\$366,312	\$371,807		\$163,612		\$208,772

Section XII

Systems Support

“We felt like the doctors really wanted to treat, and treat, and treat, and not let us have our daughter at home to die...in peace . . .” -Focus group participant

We are currently working with staff in the Division of Health Care Financing (the Medicaid single state agency) and the Department of Human Services to identify the changes that will be needed in eligibility, claims, and Medicaid reporting systems to support and accommodate the design and other special features of the Promoting HOPE Program. These features are outlined below including the systems that will be modified. All needed changes will be made before implementation of each phase of the program. See Table XII –1.

Table XII -1 Promoting HOPE Program Features that May Require Systems Support

	Feature	System
Eligibility	Identify Promoting HOPE enrollees who qualify based on the Medicaid State Plan.	PACMIS New aid categories
	Identify Promoting HOPE enrollees who qualify based on the Proposed State Plan Hospice (institutional criteria) Amendment	
	Identify Other Promoting HOPE enrollees in the expanded group (fee group)	
	Track collection of fees and eligibility	
	Family members may receive counseling up to 18 months after child's death	
Services	Promoting HOPE services will be available only to Promoting HOPE enrollees.	MMIS & MMCS codes, provider type & number, modifiers, PA edits
	All Promoting HOPE services will be authorized by the Care Coordinator	
	Expanded group will have access to <u>only</u> Promoting HOPE scope of service (limited scope of benefits, not all Medicaid benefits)	
	In the Family Choice Option, Medicaid will make an authorized payment to the contracting Fiscal Agent on behalf of the child. The family hires the surrogate caregiver and the Fiscal Agent pays the approved surrogate from the payment account set aside for the child	
Payment	Except for palliative care consultation and family-choice option, all other Promoting HOPE services will be provided through an approved home health or hospice agency. The agency will be responsible to ensure caregivers meet established criteria per the provider manual.	MMIS
	Fee-for-service reimbursement rates to be established.	
	Promoting HOPE enrollees who are also in a managed care plan will be able to access Promoting HOPE services on a fee-for-service basis.	
	Managed Care is <u>not</u> mandatory for Promoting HOPE enrollees in the expanded groups.	
	Family Choice Option—payment made to fiscal agent on behalf of the child.	
Reporting	Track enrollment, aid category, demographic information, utilization and expenditures.	Data Warehouse, MMCS, MARS
	Utah Algorithm—automate diagnosis selection process	
	Profiling to outreach to Medicaid Eligibles based on hospital utilization, diagnosis, <i>etc.</i> .	
	Annual tracking of expenditures for Promoting HOPE enrollees to track budget neutrality over five-year period.	
	Track savings from one year to another	
	Evaluation Surveys	PCs

Section XIII Implementation Schedule

“[It is] taboo... to lose a child. You are isolated. You feel like you have the plague. [People are] afraid to talk to you. They pretend your child never existed.” -Focus group participant

Expected Implementation: July 1, 2003	2002	2003			
o = start of task; x = end of task	Sept-Dec	Jan-Mar	Apr-Jun	Jul-Sep	Oct-Dec
1115 Research & Demonstration Proposal					
1. <i>Develop and Submit Proposal</i>	o				
Prepare copies and submit to CMS	x				
2. <i>Obtain Approval</i>		o			
Respond to questions from CMS, etc.					
Revise 1115 as needed to obtain approval			x		
Support for Administrative Positions, etc.					
2. <i>Legislative/Agency Funding</i>	o				
Meet with legislative coalitions, agency heads to obtain support					
Obtain agreement and implement final strategy		x			
3. <i>Establish Positions</i>			o		
Complete paperwork to create new positions and space					
Draft needed contracts or memorandum of agreements					
Finalize job descriptions					
Recruit for new positions					
Meet with new recruits to develop priority & communication plan			x		
Systems Support and Changes					
Meet with Bureau Directors for systems change priority	o				
Meet with system's staff to identify needed changes					
Develop plan and timeframes included needed resources					
Begin systems changes					
Test systems changes					
Train staff					x
Educational/Resource Materials for Families/Public					
1. <i>Brochure</i>	o				
Finalize Promoting HOPE brochure					
Circulate for review and approval					
Obtain bids and print brochures	x				
2. <i>Information for Families</i>	o				
Gather information currently given to families by PCMC clinics, etc.					
Determine information to be developed, purchased, etc					
Develop needed information sheets.					

Expected Implementation: July 1, 2003	2002	2003			
o = start of task; x = end of task	Sept-Dec	Jan-Mar	Apr-Jun	Jul-Sep	Oct-Dec
Circulate for review and approval					
Review and test draft materials					
Develop design, distribution, etc.					
Final approval			x		
Print and Assemble					
3. Web Site Coordination	o				
Meet with Medical Home website developer					
Develop strategy and process for coordinating Promoting HOPE information with Medical Home Project			x		
Regulatory or Policy Changes					
1. Licensing standards for pediatric patients	o				
Recommend changes in rules					
Strategize and obtain consensus from affected groups					
Finalize recommended changes					
Prepare draft rule and present to Health Facilities Committee					
Submit to Executive Director, etc for approval					
File Rule for public comment					
Rule Effective			x		
2. Eligibility & Sliding Fee Schedule		o			
Determine needed changes in eligibility policy					
Change policy and evaluate need for rulemaking					
Submit rule or policy for approval					
Train staff in policy change or procedure					
Notify clients				x	
3. Reimbursement Policy	o				
Determine needed change in reimbursement policy					
Determine changes in FFS & HMO rates					
Determine prior authorization process and interface					
Make needed systems changes					
Notify providers					
Offer training to affected providers and staff				x	
Provider Recruitment					
1. Home Health & Hospice Agencies	o				
Present Promoting HOPE at organization meetings					
Finalize standards for participation					
Mail out letters to identify interested agencies					
Invite to focus group - request for information meeting					
Develop formal enrollment process					
Obtain signed provider agreements					
Enroll providers			x		
2. Family Choice Fiscal Agent	o				
Identify and resolve liability issues and solutions					
Develop guidelines for family choice model					
Identify family choice brokers					
Invite to focus group - request for information meeting					
Develop enrollment process					

Expected Implementation: July 1, 2003	2002	2003			
o = start of task; x = end of task	Sept-Dec	Jan-Mar	Apr-Jun	Jul-Sep	Oct-Dec
Obtain signed provider agreements					
Enroll providers			x		
3. Palliative Care Consultation Groups	o				
Meet with palliative care physicians					
Determine guidelines for service					
Determine rates, coding, etc.					
Enroll providers			x		
4. Counseling, Child Life, Bereavement	o				
Identify current providers and current capacity					
Develop strategy for meeting gaps					
Foster partnerships for efficient utilization of resources					
Implement strategy				x	
Outreach/Enrollment/Coordination					
1. Referral Patterns	o				
Identify groups to educate regarding program such as PCMC Social Workers, discharge planners, parent support groups, pediatricians, Grand Rounds. other hospitals, DSPD, DCFS, Baby Your Baby, visiting nurse program, insurance, schools, large clinics, etc.					
Schedule information meetings with each group					
Based on input, develop referral form & process			x		
2. Assessment/Challenge Scale	o				
Finalize challenge scale					
Test scale and revise as needed					
Determine process for use					
Print copies and distribute					
Research assessment forms and process					
Develop assessment form and test			x		
3. Client Enrollment	o				
Develop enrollment and eligibility process					
Contact insurance companies and establish liaisons					
Compile list of enrolled home health/hospice providers,					
Develop assessment protocols			x		
4. Advisory Council Meetings					
Hold periodic planning, coordinating & information meetings	o				x
Training - Community Providers, Volunteers, Clergy					
Identify potential need		o			
Identify potential funding for training programs					
Determine existing resources (materials, experts, etc)					
Determine gaps					
Research successful teaching and training methods					
Develop training plan within available funding					
Schedule training sessions					
Conduct training, etc.					x

Expected Implementation: July 1, 2003	2002	2003			
o = start of task; x = end of task	Sept-Dec	Jan-Mar	Apr-Jun	Jul-Sep	Oct-Dec
Evaluation & Quality Assurance					
<i>1. Evaluation</i>		o			
Identify evaluation subcommittee					
Identify needed resources and budget					
Revise evaluation plan as needed after implementation					
Develop survey instruments					
Develop survey plan					
Implement survey plan.					x
<i>2. Quality Assurance</i>		o			
Identify quality assurance subcommittee					
Develop quality assurance checklists, forms, schedules					
Develop QA protocols					
Notify and train providers and clients regarding protocols					x

Section XIV Waivers

“It was hard for me, just all of a sudden [after she died] all your friends-- the nurses, the doctors-- they are all gone and you have nobody to talk to about what you went through...” -Focus group participant

The State of Utah has identified the need for the certain statutory waivers (described below) in order to assure budget neutrality and at the same time, ensure the delivery of needed services under the proposed Section 1115 research and demonstration project. We are also requesting authorization to include under the 1115 research and demonstration program, an optional group-- the terminally ill under 21-- that Utah does not currently check off as a covered group in the Medicaid State Plan. We also request waivers in association with this group.

A. Waiver of comparability in the amount and duration and scope of benefits

(1902(a)(10)(B) which will allow the state to:

1. Offer as Medicaid benefits, a unique array of non-traditional (non-state plan) services and supports referred to as Package B services as described in the proposal.
2. Establish unique provider standards and qualifications as appropriate to ensure access to needed services, while also ensuring quality and the health and safety of recipients and compliance with the cost neutrality provisions.
3. Offer Package B services and supports only to individuals certified (and periodically re-certified) as meeting the project’s approved targeting criteria.
4. Determine the scope and intensity of the services offered in Package B, based on a needs-based assessment that identifies the child’s medical diagnosis and condition, and the social, financial, geographic, and other relevant circumstances of the eligible child and his/her family.
5. If and when necessary, establish reasonable “caps” on the number of individuals/families authorized to access these benefits any point time during the waiver period.
6. Recognize the other family members (defined as the relatives and/or significant persons who reside with the child and provide physical, psychological, social, and spiritual support for the child) as indirect--if not direct-- recipients of Package B Services such as Respite (Traditional and Family Choice), Counseling, including expressive therapies for siblings and bereavement services, when the services are included in the recipient’s plan of care for the explicit purpose of sustaining and enhancing the family member’s ability to cope with the extraordinary demands inherent in their role of assisting the eligible child to remain at home. This includes the option of extending the child’s Medicaid eligibility for a period of up to eighteen months after the child’s death in order to continue to cover bereavement services provided to the family as needed and authorized in the plan of care.

7. Offer only Package B benefits exclusive of all other state plan benefits (including EPSDT) to the expansion group not eligible under the State Plan.

B. Waiver of eligibility and co-pay requirements to permit the State to establish Medicaid eligibility for a child not otherwise eligible under state plan eligibility rules, for any month when all the following apply:

1. The child has been certified to meet the medical targeting criteria.
2. The family and child (as appropriate) have chosen to receive Package B services.
3. The family has provided the required income statements and proof of health insurance coverage for the child.
4. The family has met the cost-sharing requirements (determined by the sliding fee schedule).

C. Waiver of direct payments to providers (1902 (a)(32)) to permit the State to pay a fiscal agency on behalf of providers who are recruited, hired, and trained by the family, when:

1. The family chooses the Family Choice Option for respite and “ancillary support services” and the selection is authorized through the assessment and plan of care.
2. A specified amount is allocated in the name of the child to the fiscal agent for payment to the person, who meets all the required criteria to receive such payments, selected and hired by the family.

D. Waiver of eligibility of certain provisions of “Optional Groups Other than the Medically Needy 1902 (a)(10)(A)(ii)(VII) for individuals under the age of 21 who would be eligible for Medicaid under the plan if they were in a medical institution, who are terminally ill, and who receive hospice care in accordance with a voluntary election described in section 1905(o) of the Act, to permit the State to cover this group in the expanded group under the Section 1115 Proposal in accordance with the following:

1. Proposed changes to the Eligibility Provisions for the Hospice Eligible Group--
 - a) the child meets Promoting HOPE targeting criteria (age 0 to 18) and meets the criteria for admission to a hospital or nursing facility;
 - b) the treating physician indicates that the child is expected to survive less than one year ~~six months~~ because of a life-threatening illness or condition; and
 - c) the responsible parent selects to care for the child in the home setting and selects enrollment in the Promoting HOPE program to receive the services in Package B (by either a home health or hospice agency elects hospice.

- d) ~~and agrees to forgo curative treatment~~ the child has other health insurance coverage.
- e) if admitted to the Promoting HOPE program before the age of 18, the individual would continue to be eligible for the Promoting HOPE program until they reach their 22nd birthday.

If the child meets the above criteria, parents' income and resources will not be considered in establishing the child's eligibility for the program and unlike those who do not meet the above criteria. No sliding fee will be charged for the Promoting HOPE program.

The child may access (all therapeutic and palliative services available through the Promoting HOPE program and the regular scope of other Medicaid services) ~~all Medicaid services for conditions not related to the terminal condition~~.

Like the expanded group, enrollment in an HMO will not be required if the child lives in an urban area.

2. Enrollment Process for this group - This subgroup under the Expanded Group of eligibles is primarily a way to help us better establish budget neutrality under the 1115 demonstration model. The classification will be virtually invisible to the family and child.
 - a) Physician will refer the child to the program.
 - b) When the assessment is made, and the parent is informed of the Package B benefits, the parent will be informed that if the child meets certain Medicaid eligibility then family income assessment may not be necessary and no fee will be charged for the program. If they do not meet Medicaid criteria, then other insurance is required and a sliding fee, based on income will be imposed.
 - c) To complete the enrollment process the physician will be asked to indicate the expected life expectancy of the child (i.e. less than 6 months, less than one year, two years or more) and answer questions needed to determine whether institutional admission criteria are met).
 - d) Based on the items checked the care coordinator and eligibility worker will make the decision regarding classification.
 - e) Parent will be informed whether they meet regular Medicaid criteria or Medicaid Hospice Criteria. If they do not meet such criteria they will be placed in the expanded group and other insurance coverage and fee will be required.
3. Reimbursement for Hospice - Promoting HOPE services reimbursed on a fee-for-services basis will substitute for the current hospice bundled reimbursement rate for this group.

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